



DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology Research Portfolio

1) A narrative review of the impact of peer-led interventions on levels of internalised stigma in health conditions; 2) Promoting positive coping and self-management in relation to undertaking cardiac catheterisation: learning from patients; 3) An experimental study investigating the impact of a peer delivered psychoeducation video on self-stigmatising attitudes in people with first episode psychosis.

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Research Portfolio Submitted in Part Fulfilment of the requirements for the Degree of Doctorate in Clinical Psychology – Volume 1 of 2

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Doctorate in Clinical Psychology

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May 2016

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Word counts by component

Critical Literature Review (<i>excluding tables & figures</i>)	5979 words
Service Improvement Project (<i>excluding tables & figures</i>)	4984 words
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Executive Summary	624 words
Connecting Narrative	2995 words
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Research Abstracts

Main Research Project Abstract

Background – Psychosis is one of the most stigmatised mental health problems. Individuals who experience psychosis can internalise this stigma, resulting in self-stigma where an individual's self-concept is eroded with a negative impact on recovery. Conversely, peer support has been shown to impact positively on recovery and theory suggests that this may be achieved through challenging stigmatising attitudes.

Aims – The aim of this study is to further investigate one potential mechanism underpinning peer support, that is the impact of peers on challenging self-stigmatising attitudes.

Methodology – 20 people with first episode psychosis were recruited and randomised to watch a psycho-educational video delivered either by an individual with experience of psychosis (a peer) or a health professional. Levels of self-stigma were measured before and after the video.

Results – The findings of this study did not support the hypothesis that psycho-education delivered by a peer reduces internalised stigma to a greater degree than someone without this, however, the results are underpowered and require a larger sample before conclusions can be drawn.

Conclusions – Further research is needed to better understand the effective components of peer support and to better understand the relationship between peer support and internalised stigma.

Service Improvement Project Abstract

Pulmonary Arterial Hypertension (PAH) is a chronic disease, which is monitored by a series of complex treatments including cardiac catheterisation (CATH). Evidence suggests that patients can experience CATH as anxiety provoking, however, most undergo this procedure without any formal psychological support. The current study aimed to explore patients' beliefs about the CATH procedure and to better understand adaptive coping and self-management skills. It was hoped that this knowledge would inform recommendations to improve the psychological experience and coping resources of those undertaking CATH.

Ten participants were recruited through purposive sampling and completed a qualitative interview, which explored their beliefs about CATH and factors which

enhanced coping resilience. Findings suggest that factors which increase an individual's understanding of CATH and sense of control were associated with positive coping. The results also suggest that whilst perceptions of the CATH procedure are very individual, the importance of relationships with health professionals and trust in their expertise was highlighted across participants. The findings informed service recommendations, including the introduction of a patient experience leaflet aimed at promoting positive coping in those attending the CATH procedures.

Critical Literature Review Abstract

Background – Stigma is a global phenomenon affecting many health conditions. Stigmatised attitudes can become internalised (internalised stigma), a process that can negatively impact on an individual's sense of self, their emotional wellbeing and wider life. Recently interventions have been developed to reduce internalised stigma, including interventions led by people with personal experience of health conditions (peers).

Aim – This review aimed to draw together literature on peer-led interventions for stigmatised health conditions, which have included internalised stigma as an outcome. The review aimed to synthesis interventions and their components; relate the findings to social identity theory and summarise what is known and not known about the relationship between peers and internalised stigma.

Method – Using specific search terms and inclusion criteria, this review yielded 13 papers in total. The papers were examined in terms of their methodology and findings, and common components of the interventions were collated across the papers.

Results – The results revealed methodological limitations amongst the papers and highlighted the need for replication. However, the findings suggest there is evidence that peer led interventions can impact positively on internalised stigma, if designed in the right way for the people who receive it. The key components include sharing experiences, narrative components, information provision and problem-solving.

Conclusions – Peer-led interventions present an empowering way of countering the stigma surrounding certain conditions through role-modelling recovery, sharing hopeful experiences and enhancing positive identity. Current evidence shows promise, however, more high quality research is needed to better understand this relationship and to develop effective, accessible interventions.

Critical Literature Review

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**A narrative review of the impact of peer-led interventions on levels of
internalised stigma in health conditions**

Word count: 5538

May 2016

Internal supervisors: Lorna Hogg and Emma Griffith

Target journal: This review will be submitted to Clinical Psychology Review
(Appendix A) due to its focus on review articles relevant to clinical psychology.

Abstract

Background – Stigma is a global phenomenon affecting many health conditions. Stigmatised attitudes can become internalised (internalised stigma), a process that can negatively impact on an individual's sense of self, their emotional wellbeing and wider life. Recently interventions have been developed to reduce internalised stigma, including interventions led by people with personal experience of health conditions (peers).

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Introduction

The current understanding of stigma was first conceptualised by Goffman in his 1963 book *Stigma: Notes on the management of spoiled identity*. Goffman (1963) referred to stigma as an attribute which can reduce someone “from a whole and usual person to a tainted, discounted one” (pg.3). Since then, stigma has been further defined as resulting from a combination of five components (Link & Phelan, 2006). Firstly, stigma involves the labelling of socially defined human differences and secondly the process of stereotyping, where labels are connected to undesirable qualities. Then, the process of labelling separates the stigmatised group ‘them’ from ‘us’, followed by the stigmatised group experiencing discrimination and loss of status as a rationale is created for devaluing and rejecting them. Lastly, power plays a key role in preventing the stigmatised group from reversing their status. Stigmatisation is a global phenomenon affecting many chronic health conditions including HIV/AIDS, leprosy, tuberculosis, mental health and epilepsy (Van Brakel, 2006).

Living with a stigmatised health condition not only places an individual at risk of discrimination from others, there is also evidence that over time public stigma can become internalised resulting in internalised stigma (Vogel, Bitman, Hammer, & Wade, 2013). Internalised stigma is defined as a process in which an individual’s previously held identity is lost in place of a stigmatised illness identity, for example, I have a serious mental illness therefore I am dangerous (Yanos, Roe, & Lysaker, 2010). Watson and colleagues propose that internalised stigma develops through a combination of three processes – awareness, agreement and application. They propose that an individual must first be aware of public stigmatising attitudes, they must then agree with them and apply these attitudes to themselves when they receive a stigmatised label (Watson, Corrigan, Larson, & Sells, 2007). Internalised stigma is seen as a related but separate construct to shame, defined as “an intense negative emotion that results from a person experiencing failure in relation to personal or other people’s standards, feeling responsible for that failure, and believing that the failure reflects an inadequate self” (Cunningham, Tschann, Gurvey, Fortenberry, Elle, 2002). Internalised stigma refers to the cognitive process of applying negative stereotypes to oneself, which may result in perceiving the self to be inadequate and experiencing shame.

Studies show internalised stigma is experienced by individuals with mental health conditions (Brohan, Elgie, Sartorius, & Thornicroft, 2010), HIV (Lee, Kochman, &

Sikkema, 2002), epilepsy (Jacoby et al. 1994) and Leprosy (Rensen, Bandyopadhyay, Gopal, & Van Brakel, 2011). It is likely that internalised stigma also affects many other health conditions, however, this review will focus on conditions where research is available.

Impact of Internalised Stigma

Internalising stigma can have a detrimental effect on an individual's sense of self and has been shown to be associated with lower levels of hope, empowerment, self-esteem and self-efficacy (Livingston & Boyd, 2010). Higher levels of internalised stigma are also positively related to shame (Campbell & Deacon, 2006) and depression (Lee et al., 2002; Simbayi et al., 2007). Beyond this, internalised stigma can impact on an individual's wider life with higher levels of internalised stigma associated with lower quality of life, lower levels of social support and difficulties pursuing employment goals (Livingston & Boyd, 2010). Research has also found that greater internalised stigma is associated with poorer help-seeking behaviour, poorer adherence to medication (Chesney & Smith, 1999) and difficulties engaging with psychological treatment (Vogel, Wade, & Haake., 2006). Considering that internalised stigma is associated with a range of negative recovery outcomes, it is not surprising that there have been increasing efforts to develop interventions to reduce this.

Interventions for Internalised Stigma

Interventions targeting internalised stigma have varied in their approach and length of delivery, and have included both therapist and peer led interventions involving a single treatment model or several integrated models. As yet there is no single conceptual basis for interventions (Mittal, Greer, Chekuri, Allee, & Corrigan, 2012). Evidence is growing for the use of psychological therapies for internalised stigma including acceptance and commitment therapy (Skinta et al., 2015), cognitive behavioural therapy (Lucksted et al., 2011) and narrative enhancement cognitive therapy (Yanos, Roe, & Lysaker, 2011). A recent review of internalised stigma interventions found that whilst approaches varied, internalised stigma programmes tended to have common components including: psychoeducation to dispel myths, cognitive techniques to normalise and challenge self-stigmatising beliefs, a narrative component focused on making meaning and a behavioural component designed to facilitate progressing important life goals despite stigma (Yanos, Lucksted, Drapalski, Roe, & Lysaker, 2015).

Some argue, however, that by reducing internalised stigma on an individual basis through psychological interventions, there is a danger of blaming the individual and leaving them feeling responsible for addressing the damage caused by internalised stigma (Corrigan & Fong, 2014). It is important that researchers and clinicians working in healthcare consider the wider message delivered when individuals are targeted and encouraged to change. Advocates in mental health propose that internalised stigma is a social injustice and that in order to change this, a community approach is needed focussing on increasing positive group identity and sense of pride (Corrigan & Fong, 2014). Studies have shown that those who identify positively with a stigmatised group are protected from the damaging effects of self-stigma on self-efficacy and self-esteem (Watson, 2007). Increasingly those who have experienced stigmatised health problems are being encouraged to speak out and support those at an earlier stage in their health journey. Peer support and mutual self-help programmes are being developed in various different countries to try to challenge stigma through group identity, acceptance and empowerment (Corrigan & Fong, 2014).

Peer Support

Peer support is defined as a “system of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement over what is helpful” (Mead, Hilton, & Curtis, 2001, p.135). A peer is someone who has experienced a specific health condition or stressor and shares characteristics with people from the target population; often a peer worker will be at a later stage in their recovery (Dennis, 2003). Peer support is not a new concept in chronic health conditions, however, in recent years peer support interventions have become increasingly popular and research has begun to try and understand the benefits of this support (Davidson, Chinman, Sells, & Rowe, 2006). Peer support has developed in varied ways and includes peer support groups (either face-to-face or online), peer delivered services, peer-run or operated services that are embedded within formal organisations, peer partnerships and peer employees (Soloman, 2004). Research shows that peer support can increase empowerment and self-esteem (Repper & Carter, 2011), decrease shame and isolation (Pauldel & Baral, 2015) and provides individuals with a sense of connection (Embaldeniya et al., 2013).

There have been several reviews of the peer support literature across different areas of health (Davidson et al., 1999; Embaldeniya et al, 2013; Pauldel & Baral,

2015; Repper & Carter, 2011;). These have generally focussed on the benefits and challenges of developing peer support interventions, both from the perspective of those who support and those who are supported. Reviews of peer support have highlighted that one benefit of peer support can be empowering people against stigma and challenging internalised stigma (Davidson et al., 1999; Repper & Carter, 2011). Similarly, reviews of interventions for internalised stigma have included peer led programmes as a possible way of doing this (Mittal, 2012; Yanos, 2015). However, the peer support review which highlighted internalised stigma as an outcome did so based on two of the 36 studies included and of the internalised stigma reviews only included two studies that were peer led. Additionally, reviews have tended to focus on one area of health, rather than zooming out and considering peer led interventions across health conditions. In order to better understand the relationship between peer support and internalised stigma in isolation, this review drew together research on peer support across a variety of stigmatised health conditions and focussed on its impact on internalised stigma.

Theoretical Framework

Social identity theory (SIT) may be a helpful context within which to consider how peer support may effectively counter internalised stigma. SIT proposes that our self-concept is formed through social group membership and the value and emotion attached to this membership (Brown, 2000). Once a member of a social group, SIT argues that individuals strive to maintain a positive identity within this group and differentiate themselves from other social groups (Brown, 2000). SIT proposes that our sense of self is defined both by belonging to certain groups (in-groups) and being distinct from others (out-groups) (Brown, 2000). When the group that an individual belongs to gives them a sense of meaning, stability and direction, this can impact positively on psychological wellbeing (Haslam, Jetten, Postmes, & Haslam, 2009). Conversely, if an individual's identity has to change or alter in some way this can have negative implications for wellbeing (Haslam et al., 2009). This negative effect is particularly pertinent when the change involves new membership of a stigmatised, inferior group. SIT proposes that in order to establish a coherent sense of self the individual must go through a process of forming connections between each different part of themselves (Brown, 2000). One factor proposed to be important in this process is contact with other members of the same group.

SIT proposes that how an individual responds to membership of a stigmatised group is determined by how permeable they perceive the boundaries between groups to

be, that is, whether they feel able to move from a low status position to a higher one. As well as how stable and legitimate they perceive their status to be in relation to other groups (Tajfel & Turner, 1979). If boundaries are perceived as permeable then an individual may choose to leave the stigmatised group in order to protect their positive identity and improve their status (Haslam et al., 2009). If, however, group boundaries are perceived to be impermeable, an individual is likely to engage in social creativity. This involves the stigmatised group rejecting stereotypes and seeking to create a positive sense of collective and individual identity (Haslam et al., 2009). Where group inferiority is perceived to be unstable and illegitimate, group members may also respond by identifying themselves more strongly with the group and pushing for social change (Haslam et al., 2009).

Being labelled with a stigmatising health condition is likely to pose a threat to an individual's self-concept. It could be argued, in line with SIT, that peer support offers several ways of protecting against this stigma. Firstly peers, in themselves, can personify the rejection of stereotypes (i.e., by showing it is possible to live well in spite of a stigmatised condition). Secondly, contact with peers may help people create a more positive social identity through seeking positive attributes within their group, understanding stigma and questioning its legitimacy. Thirdly, contact with peers may help individuals learn how to progress with life goals and solve problems in spite of pervasive public stigma. Peer support also involves a relationship and through this a sense of belonging and connection may be formed with other members of the stigmatised group.

This review will consider SIT alongside the literature on peer led interventions for internalised stigma with the aim of exploring what this theory might add to our current understanding of this complex relationship.

The Current Review

This review aimed to draw together literature on peer led interventions for stigmatised health conditions that have targeted or measured change in internalised stigma. As these interventions are in the early stage of development, examining peer interventions trans-diagnostically allowed research from different areas to be integrated and different ways of working may be shared across health conditions. The current review examined the different types of peer led interventions; how they related to SIT and summarised what we currently know about the impact of peer led

interventions on internalised stigma. The aims of this literature review are as follows:

- To evaluate the effectiveness of peer led interventions for internalised stigma.
- To examine the impact of study design on outcomes.
- To identify key components of interventions and themes emerging from the literature.

Method

As this was a focused literature review in a small area of research it was important to take an inclusive approach to the evidence base. Studies were included if they examined interventions that were fully or partially peer led, including peer support groups facilitated by non-peers. Studies could be either qualitative or quantitative and, no studies were excluded on the basis of quality. Similarly no limits were set in terms of the age of participants, the type of peer support or how internalised stigma was measured.

Inclusion Criteria

Studies were included in this review providing they met the following criteria:

- Quantitative or qualitative studies of peer led interventions where internalised stigma is a primary or secondary outcome.
- Focused on a stigmatised health condition including: mental health diagnoses, HIV/AIDS, leprosy, epilepsy and tuberculosis.
- Published in the English language.
- Published in the last 15 years.

Search Strategy

Relevant articles were identified by conducting searches on APA Psychnet, Pubmed and Scopus databases. After meeting with a librarian, the following terms were used in each search: 'peer' OR 'mentor*' OR 'consumer' OR 'advoca*' AND 'self stigma' OR 'self-stigma' OR 'internalised stigma' OR 'internalized stigma' OR 'felt stigma'. Collectively these searches yielded 913 articles including book chapters, theses, conference abstracts and journal articles. Titles and abstracts of each article in the search were then scanned, relevant articles were selected and any duplicates removed; this resulted in 129 articles. The abstract and methods of these articles

were then screened for relevance and those which met the inclusion criteria were included in the review. Additionally, the reference lists of the final nine papers from search and that of relevant reviews were scanned to identify further relevant studies. Finally citation searches of the final papers were conducted via Google Scholar to ensure no further relevant articles had been missed (see Figure 1 for selection process).

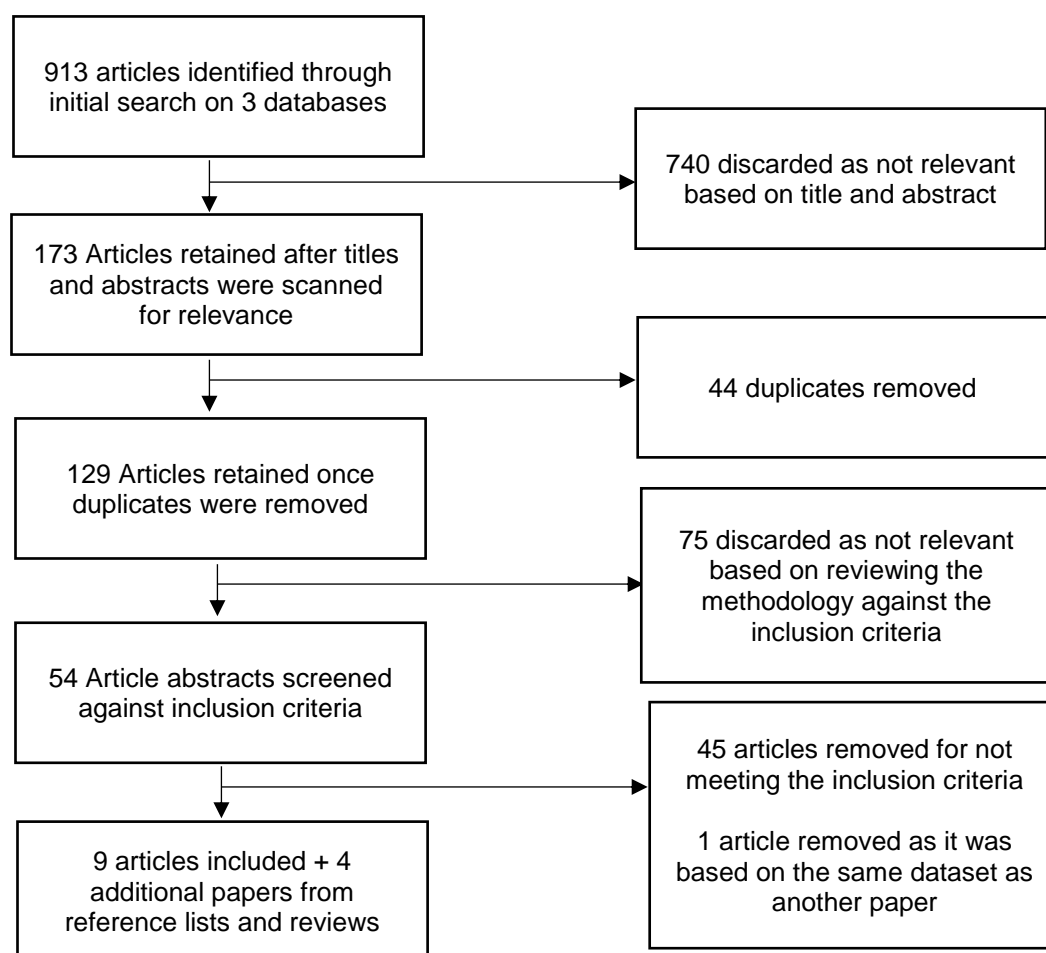


Figure 1. The article search and selection process

Results

With the exception of two papers (Harper, Lemos & Hosek 2014; Masquillier, Wouters, Mortelmans, & le Roux Booyesen, 2015) the studies included all examined interventions designed to reduce self-stigma in some way, although the manner in which they did this varied. Peer support interventions included: peer support groups, one-to-one support, a video-based intervention and multilevel interventions, which involve organisational empowerment. Tables 1 and 2 summarise the studies included in the literature review and their findings.

Table 1. Study characteristics

Author	Sample size	Sample characteristics	Stigma measure	Level of internalised stigma at baseline
<i>Barroso et al., (2014)</i> USA	100 women with HIV/AIDs	Mean age 45.9 years (SD 9.7)	- Internalised HIV Stigma Scale (IHSS). - Internal consistency = 0.93.	High levels of internalised stigma (40+ on the IHSS).
<i>Conner, Mckinnon, Ward, Reynolds, & Brown (2015)</i> USA	19 older adults with moderate to severe depression	- 63% female - Mean age 67 years (SD 5.02)	Internalised Stigma of Mental Illness Scale (ISMI)	Mean internalised stigma 63.3 indicating moderate to high levels.
<i>Corrigan et al., (2015)</i> USA	126 adults with self-reported mental health problems	- Mean age 45.6 years (SD 12.6) - 63.5% female	Self-stigma of Mental Illness Scale – 4 subscales (awareness, agreement, application and harm to self) - Internal consistency for subscales were 0.79-0.87.	Intervention group: mean internalised stigma awareness - 32, agreement - 16, application - 16, Harm - 15. Control group: mean internalised stigma awareness - 30, agreement - 18, application - 12, harm -11.(Range 5-45)
<i>DeMarco and Chan (2013)</i> USA	110 black women living with HIV/AIDS from low income backgrounds	- Mean age 44.6 years (SD 8.05)	- Berger HIV stigma scale (negative self-image subscale) - Reliability was 0.96 for the total and subscales ranged from 0.90-0.92.	Negative self-image 25.52 in the intervention and 25.17 in the control. (Range 13-52)
<i>Elafros et al., (2013)</i> Zambia	80 people with epilepsy	- Male group mean age 32.2 years (SD 8.7) - Female group mean age 30.4 years (SD 9.7) - Youth group mean age 15.2 years (SD 1.9), 44% female	- 3 item felt stigma measure adapted for use with people with epilepsy. - Internal consistency = 0.72 (Jacoby, 1994)	Men – 1.3, Women – 1.2, youth 1.79 (Range 1-3)
<i>Harper et al., (2014)</i> USA	- 50 young people newly diagnosed with HIV	- Mean age 19.24 years (SD 2.25) - 44% female	- Berger HIV stigma scale (negative self-image subscale)	Negative self-image was 34.7 (Range 13-52).

			- Internal consistency for negative self-image is 0.88.	
Livingston et al., (2013) USA	- 25 adults with a mental health diagnosis in a forensic hospital	- Mean age 42 years (SD 10.78) - 20% female	- Internalised Stigma of Mental Illness Scale (ISMI) - Internal consistency = 0.91-0.92.	Mean internalised stigma score was 2.07 indicating mild internalised stigma.
Masquillier et al., (2015) South Africa	- 294 people living with HIV/AIDS.	- Mean age 38.97 years (SD 9.34) - 75.1% female	- Berger HIV stigma scale (internalised stigma measured but negative self-image subscale) - Reliability = 0.86 – 0.88	No baseline score.
Mburu et al., (2013) Uganda	40 people living with HIV/AIDS, 10 family members and 15 health service providers.	No information	N/A	N/A
Rao et al., (2012) USA	- 24 African American women living with HIV/AIDS.	- Mean age 44 years (SD 10.0)	- Stigma scale for chronic illness (SSCI) adapted for HIV.Total based on two factors (internalised and enacted stigma). - Internal consistency = 0.93	Mean internalised stigma score of 38.0. No indication of the levels of stigma for this scale.
Russinova et al., (2014) USA	82 adults with a mental health diagnosis.	- 68 % were 40 years older or older - 68% female	Internalised Stigma of Mental Illness Scale (ISMI)	Mean internalised stigma score of 2.17 indicating mild internalised stigma.
Rüsch et al., (2014) Switzerland	100 adults with a mental health diagnosis	-Intervention group mean age 42.9 years (SD 12.7), 62% female. - Control group mean age 41.0 years (SD 9.8), 56% female.	- ISMI – excluding the resistance subscale due to low internal consistency, leaving an internal consistency of 0.92.	Mean internalised stigma scores were 2.14 for the intervention and 2.23 for the control group – both indicating mild internalised stigma.
Segal, Silverman, and Temkin (2013) USA	- Trial 1 – 505 people with a mental health diagnosis.	- Mean age 38.9 years (SD 9.9) - 46 % female	- Attitudes Towards People With Mental Illness Scale (ATPMIS). - Internal consistency 0.87 – 0.98.	Mean internalised stigma score was 53.0 in the intervention group and 53.4 in the control (Range 18-108).

	- Trial 2 – 139 people with a mental health diagnosis.	- Mean age 37.0 years (SD 9.8) - 75% female		Mean internalised stigma score was 45.0 in the intervention group and 44.7 in the control (Range 18-108).
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SD = standard deviation. IHSS (Sayles et al., 2008), ISMI (Ritsher, Otilingam, & Grajales, 2003), SSMIS (Corrigan, Michaels, Vega, Gause, Watson, & Rüsch, 2012), Berger HIV scale (Berger, Farrans & Lashley, 2001), 3 item felt stigma measure (Jacoby, 1994), SSCI (Rao et al., 2009), ATPMIS (Segal, unpublished manuscript, 2013)

Table 2. Intervention details and findings

Author	Intervention format	Intervention content	Internalised stigma findings
Randomised Controlled Trials			
Barroso et al., (2014)	<ul style="list-style-type: none"> - Participants asked to watch a video weekly for 4 weeks then as much as they like until week 12. - Control participants were given an iPod without the video. 	Video told the stories of 5 women with HIV. Content included: experiences of living with HIV, fears and benefits of disclosure and the additional stigma of being a minority woman.	<ul style="list-style-type: none"> - The intervention group showed a significantly greater decrease in internalised stigma over time compared to the control group ($p = 0.0036$). - Large effect size for reducing stigma, Cohen's $d = 0.81$
Corrigan et al., (2015)	<ul style="list-style-type: none"> - Coming out proud - a manualised peer led group intervention delivered over 3 two hour sessions - Compared to waitlist control. 	Intervention covered 3 topics: risks and benefits of secrecy and disclosure; levels of disclosure and helpful ways to tell one's story with mental illness.	<ul style="list-style-type: none"> - Significantly greater reduction in applying stereotypes to self ($f(1,42) = 6.67, <0.05$) and harm to self as a result of stigma ($f(1/44) = 6.49, p < 0.01$ in the intervention group, compared to control. - Reduction in agreement with stereotypes between over time. Intervention ($f(1,43) = 6.04, p = 0.05$), control ($f(1,66) = 3.69, p = 0.05$). - No change in stigma awareness over time or between groups ($f(2,95) = 1.78, n.s.$).
DeMarco and Chan (2013)	<ul style="list-style-type: none"> - A peer led group intervention delivered weekly over 4 weeks. - Control – peer led support group. 	Intervention involved the group watching a video from 4 women with HIV talking about their experiences and then sharing ideas, emotions and stories through structured writing. The group gave positive feedback.	<ul style="list-style-type: none"> - There were no significant between groups or over time effects ($f(2) = 1.25, n.s.$). - There was a non-significant trend towards reduced internalised stigma over time in both groups.
Masquillier et al., (2015)	<ul style="list-style-type: none"> - Peer adherence support – this 1:1 intervention involved a peer visiting the participant at home over 11 months (average of 7.6 visits per month). 	Peer support included: support with adherence to treatment, discussing barriers including stigma and treatment side effects.	<ul style="list-style-type: none"> - Having peer adherence support increased the likelihood of felt stigma ($b = 0.311, p = 0.001$)

Russinova et al., (2014)	- Photo-voice - A 10 week peer run group intervention delivered in 90 min. sessions.	Photo-voice encourages activism through photography and personal narratives. Intervention included: education about stigma and exercises to identify strengths and weaknesses and to integrate these.	- Compared to the control group the intervention group had significantly greater decreases in overall internalised stigma scores. - The photo-voice intervention had an effect size of $d = 0.55$, $p = 0.03$.
Rüsch et al., (2014)	Coming out proud - a manualised peer led group intervention delivered over 3 two hour sessions - Compared to treatment as usual.	Intervention covered 3 topics: risks and benefits of secrecy and disclosure; levels of disclosure and helpful ways to tell one's story with mental illness.	- There were no significant difference in self-stigma scores over time or between groups ($f(2) = 0.07$, $p = 0.94$.) - Internalised stigma decreased slightly over time in both groups.
Segal et al.,(2013)	Trial 1 – comparing community mental health agencies (CMHA) alone with combined CMHA plus peer led self-help agencies (SHA).	Both BSR-COSP and SHAs involved peer run drop in centres offering peer support groups, resources, social support and direct services such as counselling.	Trial 1 – those in the SHA group experienced a greater reduction in stigmatising attitudes than the control group ($b = 1.20$, $p = 0.016$).
	Trial 2 – comparing CMHA alone with CMHA plus board and staff run consumer operated services (BSR-COSP).	BSR-COSP differed from SHA in having a higher degree of staff control. SHAs involved their members in all decision making.	Trial 2 – those in the BSR-COSP group experienced a greater increase in stigmatising attitudes than those in the control group ($b = -4.73$, $p = 0.031$).
Pre-post study designs			
Conner et al., (2015)	- Peer educators (PE) matched on age, gender and location. - Meet with participants on a 1:1 basis a minimum of 3 times over 3 months.	Peers were trained in motivational interviewing, gave information about depression and treatment, shared their experience of depression and recovery and provided social and emotional support.	- Significant reduction in internalised stigma over time ($t = 2.566$, $p < 0.05$). - Four main themes identified as the benefits of PE – age related concerns, shared understanding, improved mental health literacy and mutual support.

Elafros et al., (2013)	<ul style="list-style-type: none"> - Peer support groups facilitated by a researcher and chaired by a group member. - Groups met monthly for 2 hours over a year period. - Groups organised by age and gender. 	Content of discussions included: sharing life experiences, problem solving and coping strategies.	<ul style="list-style-type: none"> - Youth group – Levels of felt stigma significantly decreased over time ($t(20) = 2.1$, $p = 0.054$.) - There was a non-significant decrease in felt stigma for adults ($t(17) = -0.3$, $p = 0.8$).
Harper et al., (2014)	- A 9 week group-based behavioural intervention co-facilitated by a peer.	Content included: providing information on HIV and legal aid, problem solving skills and role-play around disclosure concerns, peer sharing their story.	- Negative self-image improved between baseline and end of intervention with a small effect size of Cohen's $d = 0.18$.
Rao et al., (2012)	- Unity workshops – this manualised, peer led group intervention was delivered in 4-5 hour workshops over 2 consecutive days.	Content included: trigger videos, discussing what stigma meant to them, relaxation and self-care, sharing coping strategies, problem solving and role play assertive responses.	<ul style="list-style-type: none"> - There was a non-significant decrease in total stigma scores over time (T1-T2 - ($t=2.1(20)$, $p = 0.054$), T1-T3 - ($t=1.9(18)$, $p = 0.067$). - Intervention has a small - medium effect size for the intervention (Cohen's $d = 0.42$).
Naturalist, prospective design			
Livingston et al., (2013)	<ul style="list-style-type: none"> - 3 component intervention including: a peer support worker (PSW), peer led research team and a peer advisory committee. - The PSW ran weekly mutual support groups (60 mins) and provided individual peer support (5-30 mins in length) over 19 months. 	- Peer support involved discussing recovery issues and the peer sharing their experience of recovery.	<ul style="list-style-type: none"> - Significant correlation between peer support and positive change in internalised stigma over time ($r = -0.43$, $p < 0.05$). - Those who participated in the peer support experienced a decrease in internalised stigma compared to those who did not ($t(21) = 2.21$, $p < 0.05$).
Qualitative study			
Mburu et al., (2013)	- Community groups of people with HIV/AIDS implemented community based HIV prevention, care, treatment and referral.	- Peers provided education, support to attend HIV clinics and counselling family members on caring for the person without prejudice and performed HIV sensitisation campaigns in the community.	<ul style="list-style-type: none"> - Themes – Collective self-efficacy, resistance to stigma and outcomes of collective self-efficacy and resistance to stigma. - Activities of groups were seen to provide skills to cope with external stigma and confidence to overcome internalised-stigma.

Study Findings

Randomised controlled trials. Eight of the studies reported in seven of the papers (Barroso et al., 2014; Corrigan et al., 2015; DeMarco & Chan, 2013; Masquillier et al., 2015; Rüscher et al., 2014; Russinova et al., 2014; Segal et al., 2013) used an RCT design, six of these were adequately powered and one study was slightly underpowered to detect significant results (Rüscher et al., 2014). Of the powered RCTs, four studies found a significant reduction in internalised stigma following a peer-led group, video or multilevel intervention. There were mixed results among the remaining RCTs however, with two finding non-significant reductions in stigma over time (DeMarco & Chan, 2013; Rüscher et al., 2014) and two reporting an increase in internalised stigma (Masquillier et al., 2015; Segal et al., 2013). It is important to note with Masquillier and colleagues' (2015) findings that the primary aim of the peer intervention was to increase adherence to HIV medication by reducing internalised stigma. This is a notably different aim to many of the other interventions and may have impacted on the content of the intervention and how it was received. Similarly findings from Segal and colleagues' (2013) second trial reveal an increase in stigma in those who received the multilevel intervention with greater health professional control. This finding requires further investigation but could suggest the importance of services being consistent in involving peers at all levels of organisations.

RCTs represent a gold standard design to produce robust findings and the results of the above RCTs reveal a mixed evidence base. The positive results of the four studies provide promising evidence for peer led interventions, however, it is important to note the remaining four RCTs found either non-significant reductions or increases in internalised stigma. The findings of Masquillier et al., 2015 and Segal et al., 2013 highlight that peer led interventions do not always positively impact on internalised stigma and suggest the importance of considering the purpose of interventions and the consistency of peer involvement at all levels. There are a number of methodological considerations with these RCTs, including: the variation in intervention format and content, the variation of control groups (waiting list, treatment as usual and other forms of peer support) and the difference in levels of internalised stigma at baseline. Further research should seek to address these.

Pre-post studies. Four of the studies used a pre-post design (Conner et al., 2015; Elafros et al., 2013; Harper et al., 2014; Rao et al., 2012) and two of these were powered to detect significant change over time. All of the pre-post designs found

overall reductions in internalised stigma following group and 1:1 peer interventions (Conner et al., 2015), however, the significance of findings varied. It is important to note that two of the studies were underpowered (Harper et al., 2014; Rao et al., 2012) meaning that the reduction in internalised stigma found in these studies may have reached significance providing the sample was large enough to detect this. Furthermore, two of the pre-post studies show mixed findings, with group based interventions producing significant reductions in internalised stigma for certain participants (e.g., youth (Elafros et al., 2013) and male participants (Harper et al., 2014)). This suggests the importance of tailoring interventions to fit with specific populations.

Again, the results of the pre-post studies show promise for peer led interventions, however, the lack of power in half of the studies and the mixed results for different participants suggest that further research is needed before any conclusions could be drawn. Furthermore, though pre-post designs show change in stigma occurring over time, without a control group, it is difficult to determine how much of this change is due to the intervention alone.

Naturalistic and qualitative research. One of the studies used a naturalistic, prospective design and found that involvement in a multi-level intervention within a forensic hospital produced decreases in internalised stigma, which concurrently increased in those who did not take part in the intervention ($t(21) = 2.21, p < 0.05$) (Livingston et al., 2013). Though this design has good ecological validity, the lack of random allocation could have resulted in a biased sample of people who opted to be involved in peer support. Additionally, this study was powered to detect medium to large effects but may have missed any smaller effects.

Finally three of the studies used qualitative methods of data collection, either in addition to other methods or as a stand-alone design (Conner et al., 2015; Livingston et al., 2013; Mburu et al., 2013). These studies found positive results for peer led group, 1:1 and multilevel interventions. Positive themes of peer support included empowering individuals to resist stigma and increase in their confidence to overcome internalised stigma (Mburu et al., 2013); understanding individual's context and sharing stories (Conner et al., 2015) and the importance of the peer leader as a positive role model, who increased participants' sense of hope, provided support and encouraged openness (Livingston et al., 2013). At a more systemic level, peer involvement in decisional processes and research was found to have a positive

impact in creating a sense of community, pride and empowerment and improving communication, knowledge and awareness (Livingston et al., 2013).

These qualitative findings suggest that peer led interventions can have a positive impact on individuals' experiences of internalised stigma, however, it is important to note that these findings may not be generalisable beyond the specific sample.

Measures of Internalised Stigma

The studies used a range of measures, most of which demonstrate good internal consistency, defined as 0.7-0.8 (Bland & Altman, 1997). Studies used specific measures for internalised stigma (Barroso et al., 2014; Conner et al., 2015; Corrigan et al., 2015; Elafros et al., 2013; Livingston et al., 2013; Rüsch et al., 2014; Russinova et al., 2014) and more general stigma questionnaires with subscales measuring internalised stigma (DeMarco & Chan, 2013; Harper et al., 2014; Masquillier et al., 2015). Additionally, it is important to note that two of the studies did not provide a measurement of internalised stigma alone. Rao et al. (2012) used the SSCI, which includes both enacted and internal stigma and unfortunately the authors do not separate these out when reporting their results. Segal and colleagues (2013) used a measure of attitudes toward people with mental health problems (perceived stigma) rather than measuring how attitudes are internalised. In total, seven different questionnaires were used (three in mental health, three in HIV, one in Epilepsy). This variation in use of measures within the same health condition makes it difficult to draw comparisons between the study outcomes. Future research should therefore aim to use the same standardised questionnaires in order for conclusions to be drawn on the effectiveness of peer support. In terms of HIV, this review would suggest the IHSS or Berger HIV stigma scale currently have the most robust psychometric properties and with regards to mental health the ISMI has the largest evidence base and greatest internal consistency. However, the SSMS has the potential to examine different stages of internalising stigma.

Levels of Internalised Stigma

In addition to the variation in the measures used to assess internalised stigma, there is also variation in levels of internalised stigma at baseline. For studies where there was information available to determine the level of self-stigma, there were two studies (Barroso et al, 2014; Conner et al., 2015) reporting moderate to high levels, interestingly these studies found a significant reduction in internalised stigma. Of those studies with samples where stigma levels were known to be mild at baseline

there were mixed findings. Whilst these studies require further replication, these preliminary results suggest levels of internalised stigma at baseline may be an important determinant of outcome. Further research is needed to test the effect of interventions for people with high versus low levels of internalised stigma.

Components of the Intervention

Peer led interventions vary in their content, however, common themes are shared across the different approaches.

Shared experiences. One of the key components of most interventions is that they involved contact with a peer who shared their experiences of living with a stigmatised condition; this occurred directly (Conner et al., 2015; Harper et al., 2014; Livingston et al., 2013) and via videos (Barroso et al., 2014; DeMarco & Chan, 2013; Rao et al., 2012). Qualitative findings support that this was one of the main benefits of peer support (Conner et al., 2015) and that peers acted as hopeful role-models for people (Livingston et al., 2013). However, it is difficult to determine the effectiveness of this component as no study has examined the impact of this component alone or compared against interventions in which peers are not encouraged to share experiences.

Narrative component. Over half of the studies (Corrigan et al., 2015; DeMarco & Chan, 2013; Elafros et al., 2013; Livingston et al., 2013; Rao et al., 2012; Rüscher et al., 2014; Russinova et al., 2014) included a narrative component. This involved individuals sharing stories around their experiences of stigma and, in some cases, individuals were encouraged to retell their stories integrating the different parts of themselves including their stigmatised health condition (Corrigan et al., 2015; Rüscher et al., 2014; Russinova et al., 2014). The use of narration emphasised an alternative, empowered story to the well-told stigmatised story. As narration took different forms in different interventions it is difficult to draw comparisons. However, this seems to be regarded as a key element in several interventions and further research is needed to directly test this.

Information provision. A third component, which was included in six of the interventions, was the provision of information (Conner et al., 2015; Harper et al., 2014; Masquillier et al., 2015; Mburu et al., 2013; Russinova et al., 2014; Segal et al., 2013). Information related to the health condition, recovery and treatments, dispelling myths surrounding the condition and educating individuals around their rights as a

way of protecting against wider discrimination. It is difficult to determine the effect of this information provision alone as it was delivered alongside other components, however, qualitative findings from Conner and colleagues (2015) support that the increase in mental health literacy was one of the benefits of working with a peer educator.

Problem-solving. Eight of the interventions also involved a problem-solving component (Barroso et al., 2014; Corrigan et al., 2015; Elafros et al., 2013; Harper et al., 2014; Masquillier et al., 2015; Rao et al., 2012; Rüschi et al., 2014; Russinova et al., 2014). Problem solving included discussing ways of managing stigmatising situations and sharing coping strategies. Within several of the group interventions, role-play was also used to help members practice how they would manage different scenarios that they might encounter (Corrigan et al., 2015; Harper et al., 2014; Rao et al., 2012; Rüschi et al., 2014). This was particularly surrounding disclosure of their health condition and encountering discrimination. Problem solving seems to be key to a number of interventions, however as with the previous components, we cannot determine the influence of this component alone.

Whilst not a main theme of interventions, two studies have intervened with internalised stigma through organisational empowerment. This seems to have been effective when peers were involved at all levels including decision making and presents an interesting area for further research.

The key components identified here suggest that there are themes across the varied interventions and that these could be grouped into peer-specific components (shared experiences and narratives) and more generic components (problem-solving and information provision). Whilst no study has evaluated these components in this way, it would be interesting for further research to examine the effectiveness of peer specific versus generic components and how the different components might interact with one another.

Discussion

Overall the findings of these preliminary studies must be treated with caution due to the methodological limitations and need for further replication. There is, however, promising evidence among these studies that peer support can impact positively on internalised stigma. Group interventions have the most robust evidence to date, yet the results for pre-post and qualitative findings show 1:1 peer support can also be very powerful for some individuals and this needs to be further examined. The results also reveal, however, that peer support can negatively impact internalised stigma if it is not designed in the right way for those who receive it. Furthermore, some of the findings suggest peer led interventions may make no significant difference to levels of internalised stigma. These negative and neutral findings raise important issues for the peer support and require further investigation.

This review has included studies with different designs, varied statistical power, samples with different levels of internalised stigma and varied measures for assessing this. Furthermore, the interventions within these studies vary in terms of format and content, as do the control groups to which study findings are compared. These inconsistencies within the current evidence base make it difficult for conclusions to be drawn regarding the relationship between peer support and internalised stigma. However, this is the first known review to examine this relationship in isolation and these findings add to our understanding of the current evidence base, give pointers as to what might be clinically useful and suggest possible directions for further research.

This review has drawn together key components across the varied interventions, these include shared experiences, narrative components, information provision and problem solving. There is some similarity between these components and those highlighted in reviews of clinician-led interventions for internalised stigma (Mittal et al., 2012; Yanos et al., 2015). For example, both emphasise the importance of information provision to dispel myths and a narrative component to create meaning and integrate aspects of self. Crucially, however, peer led interventions differ from clinician led interventions in that they do not focus on altering the thinking patterns and behaviour of individuals, rather they aim to create an environment where experiences are shared, stereotypes are questioned, and a positive sense of collective and individual identity can be formed.

Furthermore, the peer led interventions in this review suggest novel ways of intervening to reduce internalised stigma, such as using videoed stories and intervening through organisational empowerment. The results of a video intervention illustrate that this format has the power to reduce internalised stigma in those experiencing particularly high levels of HIV stigma. As this approach has the potential to reach many people and reduce internalised stigma on a wider scale, it is important that researchers gather further evidence for this. Secondly, the findings of studies which have examined organisational empowerment as a means of reducing internalised stigma, reveal that how services are set up can contribute to the experience of internalised stigma. Studies which empowered peers to take up positions as decision makers within organisations show that this impacts positively on those using the service. This finding adds support to previous arguments that stigma is a social injustice requiring a broader community response, rather than individual intervention (Corrigan & Fong, 2014). It also supports the Recovery Model's argument for organisational transformation where peers are employed at all levels of an organisation to make recovery visible and change the existing culture (Slade, 2009).

Exploring the Usefulness of SIT

Social identity theory (SIT) provides a useful theoretical framework within which to consider the components of peer led interventions for internalised stigma. Peer led interventions, by their definition, all involve contact with another member or members of the stigmatised group. According to SIT, contact in itself allows individuals to begin to find positive similarities with other group members. This process may be further enhanced by peers sharing their experiences of encountering and confronting stigma, in line with SIT, sharing this information may encourage the rejection of stereotypes and the consideration of a more empowered sense of identity. It is also important to note that each peer led intervention also involved peers in a position of authority, and in some cases, peers taking on a significant leadership role within an organisation. Arguably, peers taking on positions of power adds strong counter evidence to support the rejection of stereotyped identities marked by inferiority.

Many of the peer interventions included an element of information provision, particularly to dispel myths surrounding stigmatised conditions and to help people become aware of their rights. SIT proposes that the acquisition of knowledge can help people identify with and integrate parts of themselves (Amiot, De la Sablonniere, Terry, & Smith, 2007). Several of the studies in this review also included a narrative component, through which individuals were encouraged to tell their stories with both

the positive and negative aspects of living with a stigmatised condition. Arguably this process also fits well with SIT, which proposes that in order to develop a coherent, balanced sense of self it is important that individuals form connections between the different elements of their self.

Considerations for Further Research and Clinical Practice

Whilst SIT provides a valuable theoretical explanation for how peer support may be effective in reducing internalised stigma, it does not explain all components of interventions and has not been directly tested within these studies. Positive identification with the stigmatised group was undoubtedly encouraged within the peer-led interventions, however, this has not been formally measured and so it cannot be concluded that this was the mechanism underpinning improvements in stigma. Further research should aim to measure levels of positive identification with the stigmatised group and examine whether this moderates the relationship between peer support and reduced internalised stigma.

Additionally, with regard to the negative findings of peer support, it is important to further investigate whether positive identification with the stigmatised group is always a positive experience. Tajfel and Turner (1979) proposed that if boundaries between groups are seen as permeable an individual may choose to leave the group, rather than identify strongly, in order to protect their identity. Whilst having a stigmatised health condition may not present a permeable boundary, it is possible that the hidden nature of many conditions allows the individual to move between identifying strongly with that part of themselves and not. Research is needed to investigate the negative effects of peer support, particularly focussing on who is likely to experience these and understanding why.

In line with SIT, many of the interventions described within this review attempt to promote positive identification through social creativity, i.e., rejecting stereotypes and creating a positive sense of identity. However, SIT also proposes that group members can respond to stigma by pushing for social change (Haslam et al., 2009). This highlights the need to think broadly about stigma and how interventions could be designed to empower people to not only counter the effects of internalised stigma but also to challenge stigma more broadly, as in Coming out Proud interventions (Corrigan et al., 2015; Rüsch et al., 2014). Within the literature there is often a separation between public stigma and internalised stigma interventions; SIT would

argue that real social change may come from empowering stigmatised groups to intervene themselves with public stigma.

This review highlights that the evidence base for peer led interventions for internalised stigma is really in its infancy and a number of key findings have been highlighted for further consideration.

- Though internalised stigma affects many health conditions, much of the research so far is limited to mental health and HIV/AIDS. As the evidence base develops, it is important that further areas are investigated and findings are shared across health conditions.
- This review highlights the need to address the current methodological limitations within the literature by designing high quality powered trials, which use validated measures of internalised stigma and measure interventions against consistent control groups.
- Further research should also aim to determine the effective components of peer-led interventions, including those highlighted within this review as beneficial e.g. shared experiences, use of narrative components, problem solving and information provision.
- As peer led interventions continue to develop, it is important that there is increased understanding of the mechanisms underpinning their effectiveness and how these relate to wider theory.
- Similarly as peer led interventions continue to develop, it would be valuable to compare these with clinician led equivalents to further understand the unique impact of peer leadership.
- Further research should also seek to understand for whom peer interventions are most effective and when, and to examine whether peer support can have a detrimental impact on internalised stigma.

Limitations

It is important to note that this review had a number of limitations. Firstly, the exclusion of studies that were not published in English may have limited the breadth of the review and the degree to which the findings can be generalised. Secondly, as the review did not measure or exclude on the basis of study quality, this may have impacted the robustness of the mixed study findings. As the evidence base continues to develop and expand, future critical reviews should seek to take a more systematic approach to the literature. Finally, though this review has applied SIT to the findings, it must be noted that there was no single conceptual basis for the peer support

interventions that were included. Whilst this reflects the current nature of the evidence base, it makes it difficult to conclude on the impact of peer led interventions on internalised stigma.

Conclusion

With increasing awareness of levels of internalised stigma across different health conditions and the negative outcomes associated with this, it is important that researchers and practitioners continue to consider this issue. Peer support presents a empowering way of countering the negative stigma surrounding certain conditions through role-modelling recovery, sharing experiences of hope and enhancing individual's positive sense of identity. At present, the evidence for peer support for internalised stigma shows promise, however, further high quality research is needed to better understand this relationship and to develop effective, accessible interventions.

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Service Improvement Project

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Promoting positive coping and self-management in relation to undertaking cardiac catheterisation: learning from patients

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Internal supervisor: Dr Cathy Randle-Phillips and Dr Andrew Medley

External supervisor: Dr Jackie MacCallam

Target Journal: This study will be amalgamated with Cara Roberts-Collins' parallel project and the joint article will be submitted to Social Science and Medicine journal (see Appendix B for author guidelines). This journal was chosen due to its interest similar research. This paper has been written up for university submission and will be amended prior to journal submission.

Statement of authorship

This service improvement project was part of a joint piece of work with Cara Roberts-Collins. Cara and I were involved in developing the idea of joint projects which would capture the experiences of staff and patient's in parallel. Each of us reviewed our literature separately and wrote our introductions separately, however, we shared similar aims in order to be able to compare and combine our findings when making recommendations back to the service. We collaboratively developed our interview structures so that they would mirror each other and were both guided by the same theoretical framework. However, we completed our data collection, analysis and discussion of our findings entirely separately and finally collaborated on the recommendations made back to the service. Both projects will be written up as one paper for publication.

Abstract

Pulmonary Arterial Hypertension (PAH) is a chronic disease, which is monitored by a series of complex treatments including cardiac catheterisation (CATH). CATH is delivered under local anaesthetic and involves inserting a catheter into a blood vessel in the arm, neck or thigh. Evidence suggests that patients can experience CATH as anxiety provoking, however, most undergo this procedure without any formal psychological support. The current study aimed to explore patients' beliefs about the CATH procedure and to better understand adaptive coping and self-management skills. This knowledge was then used to inform recommendations to improve the psychological experience and coping resources of those undertaking CATH.

Ten participants were recruited through purposive sampling and completed a qualitative interview, which explored their beliefs about CATH and factors which enhanced coping resilience. Findings suggest that factors that increase an individual's understanding of CATH and sense of control were associated with positive coping. The results also suggest that whilst perceptions of the CATH procedure are very individual, the importance of relationships with health professionals and trust in their expertise was highlighted across participants. The findings informed service recommendations, including the introduction of a patient experience leaflet aimed at promoting positive coping in those attending the CATH procedures.

Introduction

Pulmonary Arterial Hypertension (PAH) is a chronic disease characterised by progressive raised pulmonary-artery pressure and monitored by a series of complex treatments (Wryobeck, Lippo, McLaughlin, Riba, & Rubenfire, 2007). One of the most invasive procedures PAH patients may regularly undertake is cardiac catheterisation (CATH). This procedure is administered under local anaesthetic and involves inserting a catheter into a blood vessel in the arm, thigh or neck, which is then threaded into the right or left ventricle of the heart. The CATH procedure assesses pressures within the heart and is used to diagnose PAH, as well as to monitor its progression and subsequent treatment. Whilst evidence suggests that patients can experience the procedure as very anxiety provoking (Beckerman, Grossman, & Marquez, 1995), CATH is often regarded by medical professionals as routine and, accordingly, patients will usually undergo this procedure without any formal psychological support.

Psychological Impact of CATH

Research indicates that people who are awaiting the CATH procedure can experience anxiety and emotional distress (Harkness, Morrow, Smith, Kiczula, & Arthur, 2003; Taylor-Piliae & Mollasiotis, 2001). Commonly reported anxieties include: fear of the unknown (Beckerman et al., 1995); fear of the procedure and of medical complications (Peterson, 1991); fear of the technology involved and worries about the competence of health professionals (Caldwell, Arthur, Natarajan, & Anand, 2007). Beyond the experience of the procedure itself, individuals also report fears related to the results of CATH and their future (Caldwell et al., 2007; Finesilver, 1978). It is important to note, however, that everyone experiences anxiety in relation to CATH and that, despite anxieties, the majority of people undertake the procedure without formal psychological support. Accordingly, therefore, the present study aimed to gain insight into factors that underpin the evident range in psychological coping responses.

There is a limited evidence base for managing anxiety in people attending for the CATH procedure. Studies have shown that the provision of information can be an effective way to reduce anxiety (Chair, Chau, Sit, Wong, & Chan, 2012; Mott, 1999) and good communication and interactions with healthcare staff have also been highlighted as important (Cardwell et al., 2007; Harkness et al., 2003; Lyons, Fanshawe & Lip, 2002). In addition, there is growing support for the use of music therapy in reducing patients' anxiety prior to the CATH procedure (Ghetti, 2013;

Hamel, 2001). However, to date there is very little research focused directly upon patients themselves and how they develop positive coping resources for managing the procedure.

Self-management

Recent research and Department of Health guidance (Funnell, 2010; DoH, 2001) have emphasised the importance of learning from patients and supporting self-management skills in chronic health conditions. The 'expert' patient approach (DoH, 2001) introduced the idea of 'user-led self-management' for all chronic health conditions, highlighting the need to allow patients to be key decision makers in their own care. Supporting this approach has the potential to alleviate pressure on health services and positively impact on people's symptoms, attitudes, behaviour and quality of life (De Silva, 2011). Self-management interventions may also increase knowledge, self-efficacy and improve coping (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). A recent review emphasised the importance of utilising the knowledge and skills of service users in delivering effective self-management support (Funnell, 2010).

The Current Study

This qualitative service improvement project aimed to explore patients' subjective beliefs about the CATH procedure and increase understanding of patients' adaptive coping and self-management skills. The key emphasis was on learning from patients in terms of positive coping and self-management and, in turn, sharing this information with the healthcare team in the form of recommendations to optimise the provision of psychological and emotional support around the CATH procedure.

The study drew upon the Self-Regulatory Model (SRM) as a theoretical basis (Leventhal, Meyer & Nerenz, 1980). This model proposes that people respond to health threats by forming cognitive and emotional representations, which subsequently guide their coping behaviour. Cognitive representations (or illness perceptions) consist of several components, including: perceptions of control, consequences, and coherence of understanding about one's condition (Hagger & Orbell, 2003). For example, the extent to which someone understands why they are having a procedure (coherence), whether they feel they have a choice (control), and what they perceive the consequences to be, can profoundly affect how they approach and cope with the procedure.

The SRM has demonstrated utility in explaining and predicting coping responses from emotional and cognitive representations, across various health conditions (Hagger & Orbell, 2003). For example, evidence suggests that perceived levels of control are associated with more active problem solving, whereas perceived severe consequences can be linked to avoidant coping strategies (Kemp, Morley, & Anderson, 1999; Moss-Morris, Petrie, & Weinman, 1996). Similarly with regards to medical tests, studies have revealed that levels of reassurance post-test can be predicted more by pre-test illness beliefs than anxiety (Donkin et al., 2006). This study employed the SRM to design qualitative interviews and interpret the findings.

Study Aims

- 1) To explore patients' subjective beliefs in relation to the CATH procedure.
- 2) To identify adaptive coping and self-management skills in relation to preparing for CATH, undertaking the procedure, and coping in the recovery period.
- 3) To better understand the particular challenges and difficulties that people experience in relation to undertaking the CATH procedure.
- 4) Based on patient experiences and perspectives, to formulate key recommendations for the healthcare team with a view to optimising psychological support and wellbeing.

Method

Sample

The Pulmonary Hypertension (PH) team at the Royal United Hospital (RUH) in Bath were recruited to identify patients who were approaching their repeat CATH procedure. Patients were eligible for the study if they were age 18 years or over, English speaking and had a diagnosis of Pulmonary Arterial Hypertension. As the study focussed on developing a detailed understanding of positive coping, it was decided that it would be most beneficial to include patients who had experienced multiple CATHs and could therefore draw on different experiences and the knowledge they had accumulated. For this reason and to reduce burden on new patients, those undertaking their first CATH were excluded from the study. Similarly, patients who were known to experience very high levels of distress in relation to the procedure were also excluded as the interview process and reliving their CATH experiences may have caused further distress.

The final sample were eight women and two men with a mean age of 63 years (range 24-77 years old). The participants had experienced an average of three CATH procedures in total (range 2-4).

Procedure

Between October 2014 and January 2015 purposive sampling was used to identify all eligible PAH patients at the RUH; patients were contacted by post and invited to take part in the study. Those who consented were called and an interview was arranged to take place either in person or, where that were not possible, over the telephone. In total 19 invites were sent out, 12 consent forms were returned and ten of those 12 were successfully contacted for an interview. Two people were uncontactable by phone or mail.

Prior to the start of this study, the protocol was reviewed and approved by the Ethics Committee of the Department of Psychology, University of Bath (see Appendix C) and the Lead for Quality Improvement, Division of Medicine, Royal United Hospital, Bath.

Interviews

The development of the semi-structured interview schedule was guided by the SRM theoretical framework. Interviews began with the question 'Can you tell me a bit about how you found out that you needed the CATH procedure?' and proceeded to explore participants' beliefs about the procedure, their perceived control, emotional responses and how they coped (see Appendix D for the interview schedule). Interviews lasted 30-60 minutes in total. All participants provided written informed consent to have their interview audio recorded and recordings were transcribed verbatim by CA.

Data Analysis

Transcripts were analysed using thematic analysis as its flexibility allowed the analysis to be guided, but not constrained, by the SRM and to reflect the reality of patients' experiences with CATH and the meanings that they made of these (Braun & Clarke, 2006). In line with guidance from Braun and Clarke (2006) a number of decisions were made prior to commencing data collection. The analysis focused on a detailed account of one aspect of the data, namely patients' subjective perceptions of CATH and the factors which enabled them to develop adaptive coping strategies. The analysis was theoretically driven by the SRM and within this an essentialist/realist approach was adopted to examine the meaning of participants' experiences (Braun & Clarke, 2006). Themes were coded at a semantic level to reflect the reality of patient

experience and to identify broader meanings across the data-set (Braun & Clarke, 2006).

In order to become familiar with the data, audio recordings were transcribed by CA and read in written form. CA initially noted down anything of interest during the transcription process and then coded the written data in relation to the research questions. Codes were organised into preliminary themes, which were refined over repeated readings of the transcripts. Themes were grouped into superordinate (main themes) and subordinate (themes within the main theme) and organised into a thematic map (see Appendix E). The transcripts were also analysed by a second researcher and discrepancies between the researchers were discussed before the themes were finalised. There was good agreement between both researchers.

Results

The analysis identified four superordinate themes which were: the individual process, experiences, trust in expertise and feeling connected. Each of these themes contained a number of subordinate themes (see Table 1 for themes and Appendix F for all quotes).

Table 1. The superordinate and subordinate themes

Superordinate themes	Subordinate themes
<i>Individual process</i>	<i>Strengths</i> <i>Vulnerabilities</i>
<i>Experiences</i>	<i>The CATH journey</i> <i>Wider health experiences</i>
<i>Trust in expertise</i>	
<i>Feeling connected</i>	<i>Being involved</i> <i>Kindness</i> <i>Shared experience</i> <i>Faith and support</i>

Individual process

The data revealed the profoundly subjective and idiosyncratic nature of appraisals and coping responses in relation to the CATH procedure; there was no one way to experience it. Whilst this theme runs through the remaining themes, there were two specific subordinate themes which seemed particularly relevant to the individual process: these were personal strengths and fears.

Fears. The expression of fear regarding the CATH procedure was highly variable, with some people reporting an absence of fear, others reporting fears initially and some experiencing sustained fears. One of the main fears expressed was fear of the unknown. Participants discussed how, even with thorough explanations of the CATH procedure, there was an almost inevitable fear of the unknown, which could only really be allayed by going through the procedure.

I knew more or less what to expect it's just that little bit of nervousness before you go in to have the procedure because although it's explained you still don't know how you're going to react when you actually go in to have the procedure done (Interview 5)

The second main fear expressed by participants was fear of the outcome. Unlike the fear of the unknown, this fear tended to be more long-lasting and related to participants' wider health experiences. Some viewed it as a fear that may never go away.

I think it's probably going to be the same going into future ones because I think the worry's always going to be – have I got worse? Have I got better? Are they going to increase the medication? Are they going to take me off the medication? Yeah things like that... (Interview 7)

Those who reported no fears around the procedure expressed anxieties about the practicalities of getting to the hospital and about waiting around for the procedure.

They forget you're suffering with breathing problems and you have to walk miles to get to each place...and the car parks that's the biggest problem of all (Interview 6)

Strengths. In terms of individual strengths, the theme of acceptance was evident throughout a number of participant responses. Acceptance seemed to be

important in helping people to cope but how this was expressed differed between people. For some people acceptance was very matter of fact and talked about as being a straight forward process.

Erm...I wasn't bothered...I was quite...it was a case of that's the programme for tomorrow and we're going to do it and that was it...just sort of took it in that frame of mind...I wasn't panicking or anything like that. (Interview 3)

This attitude seemed to enable participants to cope positively with the procedure, perhaps by not focusing on the risks or their anxieties. For others, acceptance was a slower process through which they experienced their fears before arriving at a point of acceptance prior to the procedure.

...but I mean going back to how you feel it's facing your demons really rather than it being lurking like will I get it? won't I get it? (Interview 2)

Another strength that participants identified was the importance of feeling informed and prepared, although how this was perceived varied greatly between individuals. Participants spoke of the importance of their own communication and information preferences; in other words, the value of knowing as much as they wanted to know. There was a sense that this helped people to feel more in control and, in turn, allayed some of their fears.

Yes I mean some people don't want to know but I'm one of those people who do like to know because you are best able to deal with it and I think that helps you get over the initial...fears or anxieties about it...(Interview 5)

Experiences

The second superordinate theme was the importance of experience in shaping individuals' perceptions and their ability to cope with CATH. Throughout the dataset it was evident that both experiences of the procedure itself and wider health experiences were influential.

The CATH journey. Participants discussed how their view of the procedure had altered over time, much like they were on a journey. There was a sense that the act of repeatedly experiencing CATH shaped the way participants would experience

the procedure in future. When this occurred positively, participants talked of an increase in their confidence and understanding of CATH over time.

Well I didn't know what was going to happen the first time anyway and the only thing I thought this time was it couldn't have been too bad because I've had it done before... (Interview 6)

This enabled people to feel more in control of the procedure, in so much as they would know what to expect and feel able to ask for their needs to be met.

Exactly. Knowing where you're going and lying up in the place whilst they organise all the materials and all the equipment and things round you and to know to say to them 'it's cold in this room give me an extra blanket round my feet'. (Interview 3)

For others, the CATH journey involved complications. These may have been a procedural difficulties during CATH or a sudden feeling of panic in the CATH lab. Either way, experiencing complications was linked to a journey which involved increased fear over time and a reduction in self-belief regarding capacity to cope.

...and then the third one...I got really panicky when I was having it done and when I came to the fourth time I really didn't want to have it done I really got a sort of phobia I think...it seems the more I have it done the more I feel it...(Interview 10)

Wider health experiences. Beyond the procedure itself it was clear that participants' wider experiences of challenges, either in health or more generally, influenced how they saw the procedure and how they coped. For some, who had undertaken more invasive procedures, CATH was viewed in comparison as a simple, straightforward procedure.

No it didn't worry me at all <doctor's name> put me at ease the way he explained it to me it's just a needle that isn't going to finish me off I've had a heart bypass when I was in <another hospital>...didn't bother me at all...(Interview 4)

These comparatively more serious health experiences seemed to raise the threshold for experiencing anxiety and increased a person's belief in their ability to cope, having seen what they have coped with previously.

Trust in expertise

Throughout the dataset it was apparent the faith and trust individuals placed in the expertise of medical professionals was important in helping them to cope positively. Participants spoke of the experience and skill of professionals and how this enabled them to feel more confident and reassured.

First time it was mentioned to me at <another hospital> by the consultant who thought I would be better to have it done at <study hospital> 'cause they had more experience there and did them much more regularly...erm so in that respect I felt more confident going to <study hospital> (Interview 3)

Participants also discussed the importance of trusting that the professionals were not only skilled but were also trying their best and would not attempt a potentially dangerous procedure without having a sound rationale.

It'll be alright...and you know just having that faith and trust in people with the best will in the world, I know things go wrong but you have to put your trust in people because they are skilled and you have to trust them to look after you well. (Interview 5)

Feeling Connected

Finally, it was clear that something which helped people to cope throughout the whole experience of CATH was feeling that they were connected on a human level with staff, peers, family and their faith. Participants spoke of these connections giving them strength and an ability to cope through a difficult procedure.

Being involved. Participants reflected on the importance of good communication from staff and how this helped them to feel more involved in the process. They spoke about the importance of knowing the schedule for the day and about what was happening during the procedure. There was a sense that communication had both a reassuring effect and helped people to feel connected with staff.

...think it's explaining what would happen and saying 'well there might be a bit of a wait here' and sort of keeping me up to date with when I would be due down for the procedure...so yeah keeping me informed was helpful...(Interview 8)

Kindness. Throughout the dataset it was evident that the kindness and humanity shown by staff was invaluable in helping people to cope. This was expressed by some as being a welcome distraction and source of relaxation.

Well they just chatted really about something and nothing...you know where've we come from and have we been on holiday...you know just sort of socialising a bit really...probably trying to take my mind off it...(Interview 1)

For others the importance of the staff's kindness extended beyond feeling at ease to helping people feel valued as human beings rather than being seen as patients in a busy system.

Well the friendliness of the nurses (helps on the day) and the way they talk to you and just the general friendliness in the unit...they're pleasant, they talk to you, refer to you...tell you how long it was going to be...that type of friendly attitude within the department...They treated you as a human being to chat to rather than just here's another patient get them through the system...(Interview 3)

Shared experience. Participants discussed the importance of the reciprocal process of sharing experiences with peers who have experienced the CATH procedure. This often occurred informally on the ward and was valued as a source of reassurance, seeing that someone else has got through the procedure before was seen as important in helping participants cope.

As I say if people ask me when they're waiting to go I say 'no it's fine honestly' because someone did that to me the first time and it got me through the first one...(Interview 10)

Faith and support. Feeling supported was also highlighted as important in helping participants feel connected and consequently better able to cope. Family and partners were spoken about as being an important presence in helping people to feel they were not going through the CATH alone.

Well she was just there for me really that was the main important thing that I wasn't there on my own...I think that was the main thing because it would have been difficult if I would have had to go home and cook my dinner things like that so with her being there that made it a lot easier...(Interview 7)

Similarly, some participants spoke of their religious faith and the importance of this in helping them to feel they were not alone and that they could trust in their faith to get them through the procedure.

I suppose really just the feeling that although you're the one in the theatre having it done you're not on your own, it's that sense of people standing by you...you know God's on my side, my husband's on my side it's just knowing that you're sort of cared for (Interview 2)

Discussion

The results of this study provide important insights into how patients cope with the CATH procedure and how health professionals can promote coping within the PH team at the RUH in Bath. The identified themes suggest that whilst perceptions of the CATH procedure are very individual, the importance of relationships with staff and trust in their expertise spanned different patients' experiences. The themes also suggest that, in line with the SRM, factors which enhance an individual's understanding of CATH and perceptions of control were associated with positive coping. The findings of this study add to our understanding of how patients cope and promote the notion of the 'expert patient' in informing recommendations for health care teams.

Subjective Beliefs about CATH

The findings in relation to subjective beliefs about the CATH procedure support previous literature (Beckerman et al., 1995; Caldwell et al., 2007; Finesilver, 1978) in that 'fear of the unknown' and 'fear of the results' were experienced. However, interestingly some did not report these fears, perhaps due to having experienced more risky health procedures in the past or due to their 'matter-of-fact' acceptance of the CATH. Additional anxieties, whilst unrelated to the procedure itself, were concerning the practical aspects that surround the procedure, such as waiting times and parking.

Coping and Self-management

Various themes were highlighted as important in promoting positive coping. Some of these were based on individual characteristics, whereas others were dependent on relationships. One factor that was very individual was being provided with a sufficient

amount of information to enable patients to feel informed and prepared. Having sufficient information was seen to improve understanding and empowered patients to feel better able to cope. This finding supports previous research, which suggests that receiving education and information about CATH can decrease anxiety (Chair et al., 2012; Mott, 1999). However, it is important this is done on an individual basis as different coping styles – for example whether someone seeks (a ‘monitoring’ coping style) or avoids (a ‘blunting’ coping style) threat-related information – can affect how beneficial information can be (Miller, 1987). Research suggests that information provision is most effective when tailored to monitoring or blunting coping styles (Miller, 1994).

With regards to patient relationships with health professionals, the findings of this study support previous research (Cardwell et al., 2007; Harkness et al., 2003; Lyons et al., 2002) in emphasising the importance of good human interactions with staff and trust in their expertise as factors which facilitate positive coping. Findings also revealed that sharing experiences with peers can promote positive coping. Relationships with other patients who have been through the same procedure or illness (peers) has the potential to influence an individual’s appraisal of a stressful experience, both directly through information provision and indirectly through social comparison (Cohen, Underwood, & Gottlieb, 2000). There is little research into peer support for cardiac procedures, however, Parent and Fortin (2000) found that peer supported visits to hospital can significantly reduce pre-operative anxiety and increase self-efficacy in patients undergoing coronary artery bypass graft surgery.

Finally the results of this study emphasise the importance of supportive relationships with loved ones and the value of faith in empowering patients to cope with CATH. These results support previous qualitative findings that social support and spiritual beliefs can help people to cope both with ongoing chronic illness and with the surgical procedures which may accompany illness (Bin, Costa, Vila, Dantas, & Rossi, 2014).

Service recommendations

Considering the study findings a number of recommendations were made to improve the psychological experience of undergoing the CATH procedure. These were as follows:

- Individualised provision of information - Though it is necessary for health professionals to provide the information that patients need to know in order to make an informed choice about CATH, it is important to recognise and respect

individual preferences in information provision. For some, the essential information will be sufficient whereas others may wish to know more.

- Recognising the value in the professionals/patient relationship - It is important to acknowledge that professionals' communication and kindness were invaluable in promoting positive coping. It is recommended that this practice continues.
- Individual preferences sheet - It was recommended that a passport could follow the patient through their journey so that at each step professionals were aware of a patient's preferences to reduce anxiety.
- Peer support - The informal sharing of experiences on the ward could be extended by providing accounts from patients who have been through the procedure or reliable internet resources for those who benefit from seeing for themselves how the procedure looks.
- Signposting to psychological support after complications - As there was a clear link between complications (e.g. something getting stuck/panic) and increased anxiety, a system for referrals to psychology in these circumstances was recommended. Psychological work would be helpful in preventing this cycle from repeating with future CATHs.
- Practical recommendations - Patients suggested some practical recommendations to improve coping, these included: something distracting on the ceiling, a choice of music in the CATH lab and magazines in the waiting area.
- Ongoing discussion and evaluation of recommendations - It was suggested that the results of this study continue to be shared and discussed as new members join the PH team. It is important that staff continue to understand the role of the above recommendations in promoting positive coping and evaluate each recommendation over time.

Recommendations were fed back to staff in the PH and cardiac teams at the RUH. Staff reported that the themes were aligned with their experience of watching patients go through the CATH procedure. They agreed that having resources to help people know what to expect (practically and emotionally) from CATH would be beneficial. It was decided that a video and an image-based leaflet (see appendix G) would represent a helpful service improvement, in contrast to the often overwhelming amount of written information that patients receive. Staff also discussed the idea of the passport to follow patients and how this could be most effectively used. The idea was refined to be a procedure which would be followed when a patient reported high

anxiety or a history of complications during medical procedures (see appendix H), as this was linked to increased anxiety. It was decided that the passport would not be used for every patient but instead be a useful resource for those patients who were having more difficulty.

Limitations

This study focussed on positive coping in PAH patients undergoing repeat CATH procedures and excluded those who experienced high levels of distress. It is therefore necessary to be cautious about the extent to which these findings could generalise to non-PAH patients or to those who do experience high levels of distress around the procedure. Further research is needed to better understand those who experience high distress around the procedure and to determine the best support. Secondly, though the investigator was independent of the PH service, patients were initially informed of the study by the PH Consultant. This method of recruitment could have led to a biased sample of people who had positive experiences with the PH team and therefore wanted to be involved in research.

A further limitation was the mixed data collection methods. Two of the interviews were completed via telephone and eight were conducted face-to-face. Though this meant location and patient preference did not restrict involvement in the research, there is a danger that without the non-verbal communication some of the depth and richness of data could have been lost (Burnard, 1999; Chapple, 1999). Telephone interviews included in this study were shorter in length than face-to-face interviews but did allow people who may otherwise have declined, to participate in the research.

Learning Outcomes and Service Changes

Learning from patient expertise, this study has found that undergoing the CATH procedure is very individual and that perceptions of it can change over time and according to patients' wider and ongoing experiences. Factors that enhance an individual's understanding of CATH and sense of control were reported to be beneficial. These include: adequate information provision and sharing experiences with peers. The findings also highlight the importance of trust in expertise and good quality relationships with staff in helping patients to cope with an anxiety provoking procedure. The current findings may provide useful learning for other invasive hospital procedures, however, further research is needed to explore this.

On the basis of the results, this study influenced a number of service developments within the PH department. These included: the introduction of patient experience leaflet for everyone and an individualised passport to follow patients with high anxiety or a history of medical complications, as well as a procedure for referrals to be made to the team psychologist. In implementing these patient-led recommendations, the PH department is aiming to further enhance the psychological wellbeing of those who attend for CATH procedures and will continue to monitor whether these service developments have achieved this.

Conclusion

This study provides an insight into the psychological experience of having CATH and how people manage to positively cope with it. Drawing on patient experience, this study has made a number of recommendations aimed at improving the psychological wellbeing of those who attend for the CATH procedure. Further research is needed to determine whether these recommendations may be useful and applicable to other areas of clinical health.

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Main Research Project

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An experimental study investigating the impact of a peer delivered psycho-education video on self-stigmatising attitudes in people with first episode psychosis.

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Internal supervisors: Lorna Hogg and Emma Griffith

External supervisor: Dr Damian Taylor

Target journal: The final report will be reduced and submitted to Early Intervention in Psychiatry (Appendix J) due to the journal's interest in similar articles.

Abstract

Background – Psychosis is one of the most stigmatised mental health problems. Individuals who experience psychosis can internalise this stigma, resulting in self-stigma where an individual's self-concept is eroded with a negative impact on recovery. Conversely, peer support has been shown to impact positively on recovery and theory suggests that this may be achieved through challenging stigmatising attitudes.

Aims – The aim of this study is to further investigate one potential mechanism underpinning peer support, that is the impact of peers on challenging self-stigmatising attitudes.

Methodology – 20 people with first episode psychosis were recruited and randomised to watch a psycho-educational video delivered either by an individual with experience of psychosis (a peer) or a health professional. Levels of self-stigma were measured before and after the video.

Results – The findings of this study did not support the hypothesis that psycho-education delivered by a peer reduces internalised stigma to a greater degree than someone without this, however, the results are underpowered and require a larger sample before conclusions can be drawn.

Conclusions – Further research is needed to better understand the effective components of peer support and to better understand the relationship between peer support and internalised stigma.

Introduction

Psychosis is described as a severe and enduring mental health problem that affects 3.4% of the population over a lifetime (Perälä et al., 2007). It has been identified by the World Health Organisation as the third most disabling of all health conditions (WHO, 2002) due to its impact on an individual's education, employment, relationships, social inclusion and physical health. The majority of people who develop psychosis (80%) will experience their first episode of psychosis (FEP) between 15-30 years old (Van Os & Kapur, 2009). As adolescence and early adulthood are regarded as crucial times for the development of self-concept, it is not surprising that experiencing a FEP within this period can impact on an individual's sense of self and thoughts relating to future selves (Norman et al., 2014). In addition to the symptoms, people who develop psychosis are often subjected to the negative reaction of the social environment and, in particular, the stigma that often surrounds psychosis (Schulze & Angermeyer, 2003).

Stigma and Psychosis

Psychosis is regarded as one of the most stigmatised mental health problems (Angermeyer & Schulze, 2001) and people with psychosis are often associated with negative stereotypes, such as being incompetent, dangerous or unable to recover (Corrigan, Larson, & Rüsch, 2009). These stereotypes and the discrimination that accompanies them can be damaging to an individual, particularly when stigmatised ideas become internalised (self-stigma). Watson and colleagues (2007) propose that stigma is internalised through a three stage process of awareness of negative stereotypes, agreement with these and application to self. For example, if an individual is aware of stereotypes and agrees with them, then receiving a diagnosis of psychosis can suddenly make stereotypes self-relevant.

A study across 14 European countries concluded that 41.7% of people with psychosis experienced moderate-high levels of self-stigma and a further 34% reported lower levels of self-stigma (Brohan, Elgie, Sartorius, & Thornicroft, 2010). Self-stigma can have a negative impact on an individual's self-concept, eroding their self-esteem (Lysaker et al., 2008; Yanos et al., 2008) and self-efficacy (Vauth et al., 2007). This erosion of self-concept has implications for an individual's behaviour in the pursuit of life goals and how able they feel to participate in society (Link, 1982). High self-stigma is associated with poorer help seeking (Vogel, Wade, & Hackler, 2007), poorer

engagement with services (Fung, Tsang, & Corrigan, 2008); lower quality of life and difficulties pursuing employment goals (Livingstone & Boyd, 2010).

Self-stigma, however, is not an inevitable consequence of developing psychosis. Some individuals reject negative stereotypes and become energised and empowered in reaction to stigma (Corrigan et al., 1999). It has been suggested that empowerment may result from identification with positive role models within the stigmatised group. Even when stereotypes are internalised, belonging to an in-group and feeling accepted has been shown to be protective for self-esteem (Porter & Washington, 1993).

Peer Support

Peer support in mental health defies negative stereotypes and promotes the notion of recovery through positive role models (Proudfoot et al., 2012). A peer is someone who has personal experience of a health condition and is at a later stage in their recovery (Dennis, 2003). Increasing numbers of mental health services are developing peer worker roles and national guidelines for psychosis suggest that peer support should be considered as an intervention to improve an individual's quality of life (NICE, 2014).

Alongside recommendations, the evidence base for peer support in mental health is growing. Research has found those who receive peer support report greater feelings of being accepted (effect size $d = 0.46$), understood (effect size $d = 0.52$) and liked (effect size $d = 0.47$) compared to those who received support from a non-peer (Sells et al., 2006). Reviews conclude that peer support positively impacts on an individual's sense of hope, empowerment and ability to effect change in their lives (Davidson et al., 2012). Beyond this, there is evidence that peer support improves quality of life and social functioning in people with psychosis (Castelstein et al., 2008) and that, when compared to standard care alone, those who receive peer support had significantly fewer hospital admissions (effect size $d = 0.44$) (Sledge et al., 2011).

With this accumulating body of evidence, it is important to consider theoretical perspectives on peer support. Mead, Hilton and Curtis (2001) propose that the label of 'mental patient', assigned by the medical model, contributes significantly to the experience of any mental health problem. They argue that peer support is effective because it challenges the assumptions of the medical model. Peer workers themselves challenge the notion that psychosis is permanent as they have recovered

and are seen as competent to provide support. Mead et al. (2001) argue that recovery lies in undoing the cultural process of developing a mental health identity.

Another theoretical perspective that may be useful in understanding the benefits of peer support is Social Identity Theory (SIT, Tajfel & Turner, 1979). SIT, as discussed in the earlier critical review, argues that an individual's sense of self is formed from their social group membership and the significance this holds (Brown, 2000). Once a member of a social group, SIT proposes that individuals will seek to maintain self-esteem through positive identification with members of the same group (the in-group) and distinguishing themselves from non-members (the out-group) (Brown, 2000). When a group is stigmatised, SIT proposes that there are different ways an individual can respond in order to protect self-esteem. Firstly, if it is possible, they may choose to leave the in-group completely, alternatively they may choose to identify strongly with the in-group and create a positive sense of identity and/or push for social change (Haslam, Jetten, Postmes, & Haslam, 2009). Arguably peer support provides contact with the in-group and with an individual who rejects stereotypes associated with psychosis. Peer support may therefore be effective in that peers encourage individuals to identify with a more positive sense of individual and collective identity.

Few studies have directly tested either of these theories in relation to peer support and the active ingredients of peer support remain under-researched (Davidson, Chinman, Sells, & Rowe, 2006), however, research from qualitative studies offer some insights. In a study of peer workers, it was reported that peers believed their support was effective because it altered individuals' stigmatised attitudes and fostered hope (Mowbray, Moxley, & Collins, 1998). Additionally, qualitative studies of stigma highlight the importance of peer support in exiting from the negative cycle of stigma (Pyle & Morrison, 2014) and facilitating recovery (Peterson, Barnes, & Duncan, 2008).

In summary, theory and qualitative findings suggest that peer support may be effective because peers challenge the stigma that people often experience with a mental health diagnosis. Models of stigma may therefore be useful in conceptualising the process by which peer support impacts on recovery outcomes such as quality of life.

The 'Why try' model

The 'why try' model, developed by Corrigan, Larson and Rusch (2009), proposes that the demoralisation and devaluation which results from self-stigma erodes a person's

self-worth (self-esteem) and belief in their ability to achieve goals (self-efficacy). This can impact directly on goal related behaviour and indirectly on life goals through its negative impact on engagement (see Figure 1). The model also proposes that empowerment serves as a positive mediator between self-stigma and recovery outcomes. By providing role models who directly contradict negative stereotypes, peer support may alter self-stigma, leading to improved recovery outcomes.

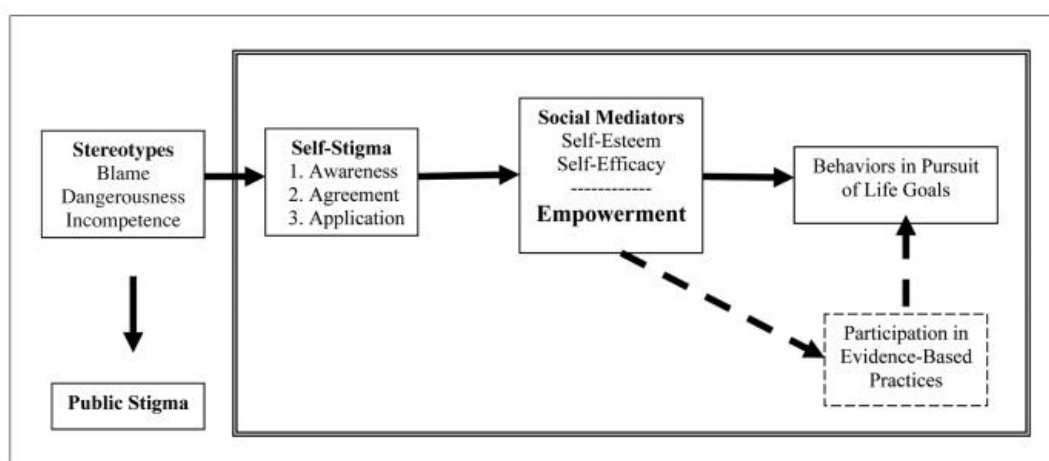


Figure 1 The "why try" effect

Figure 1 illustrates the 'why try' model (Corrigan et al., 2009, p.76)

As peer support becomes more widely used it is essential that we test the theories regarding its efficacy. Qualitative studies (Mowbray, Moxley, & Collins, 1998; Pyle & Morrison, 2014) suggest that one way in which peer support exerts a positive impact on recovery is through altering stigmatising attitudes. The present study seeks to further explore this using a simple experimental protocol involving psycho-educational videos.

Psycho-education to Challenge Stigma

There is evidence suggesting that educating people about psychosis can alter their stigmatised attitudes towards people experiencing psychosis (Corrigan, Morris, Michaels, Rafacz, & Rüsch, 2012). By presenting children with a brief video dispelling misperceptions of psychosis, Brown and colleagues found a reduction in stigmatising attitudes, which was maintained one week later (Brown, Evans, Espenschade, & O'Connor, 2010). Similarly, French and colleagues (2011) found that a 15 minute podcast normalising psychotic experiences reduced people's stigmatised views of psychosis. Research also suggests that psycho-education for those experiencing psychosis and their families can be beneficial to a number of outcomes including:

improving quality of life; adherence to medication and reducing relapse and readmission (Pekkala & Merinda, 2011).

The Current Study

Theory and evidence suggests that peer support may impact positively on recovery through undoing the harmful effects of stigma and empowering individuals. This study aimed to test this, guided by the 'why try' model. Crucially, this study examined whether psycho-education had a greater impact on self-stigma when delivered by someone who has actually experienced psychosis and personifies recovery compared to a professional with no personal experience of psychosis. Consistent with the 'why try' model, self-stigma was defined as awareness of stereotypes, agreement with these and application of these to the self. As stereotypes were not explicitly discussed in the videos it was not anticipated that this would change over time. However, theory suggests that peers challenge stigmatising attitudes held by individuals and applied to themselves, thus a change may be expected in stigma agreement and application.

Hypotheses

1. Between time one (T1) and time two (T2), those in the peer condition will experience a greater reduction in two aspects of self-stigma (stigma agreement and application) compared with those in the professional condition.
2. There will be no change in the third aspect of self-stigma (awareness of stigma) in either condition.
3. At time 1 there will be an association between levels of self-stigma, social mediators (self-esteem, self-efficacy and empowerment) and goal directed behaviour.

Method

Design

An experimental between and within participants design was employed to investigate the hypotheses. Participants were randomly assigned to one of two conditions, which involved listening to either a peer or a professional talking about psychosis, the Early Intervention in Psychosis Service (EIS) and recovery. Participants completed questionnaires before and after watching the video. This study was approved by the National Research Ethics Service Committee North West Ref. no. 15/NW/0517 (See Appendix K).

Participants

Twenty participants were recruited, using convenience sampling, through Avon and Wiltshire and 2Gether (Gloucestershire) mental healthcare trusts (see Figure 2 for consort). Participants were selected based on the following criteria.

Inclusion criteria.

- Currently an outpatient with an EIS
- Aged 18 years or over
- Clinical diagnosis of psychosis

Exclusion criteria.

- Experiencing acute distress, based on care-coordinator's clinical judgement, which would prevent engagement with the experimental task and questionnaire completion.
- Unable to understand spoken English.

The sample size was lower than anticipated, however, the following steps were taken in an attempt to maximise recruitment over the study period. The researcher established and maintained contact with eight clinical teams who agreed to be involved in identifying eligible participants. A named contact for each team was appointed and the researcher met with teams to identify barriers to recruitment. Responding to the feedback that a main barrier was competing clinical and research demands, the researcher collaborated with a colleague's research recruitment and amended the study to allow for participants to be recruited directly from recovery groups.

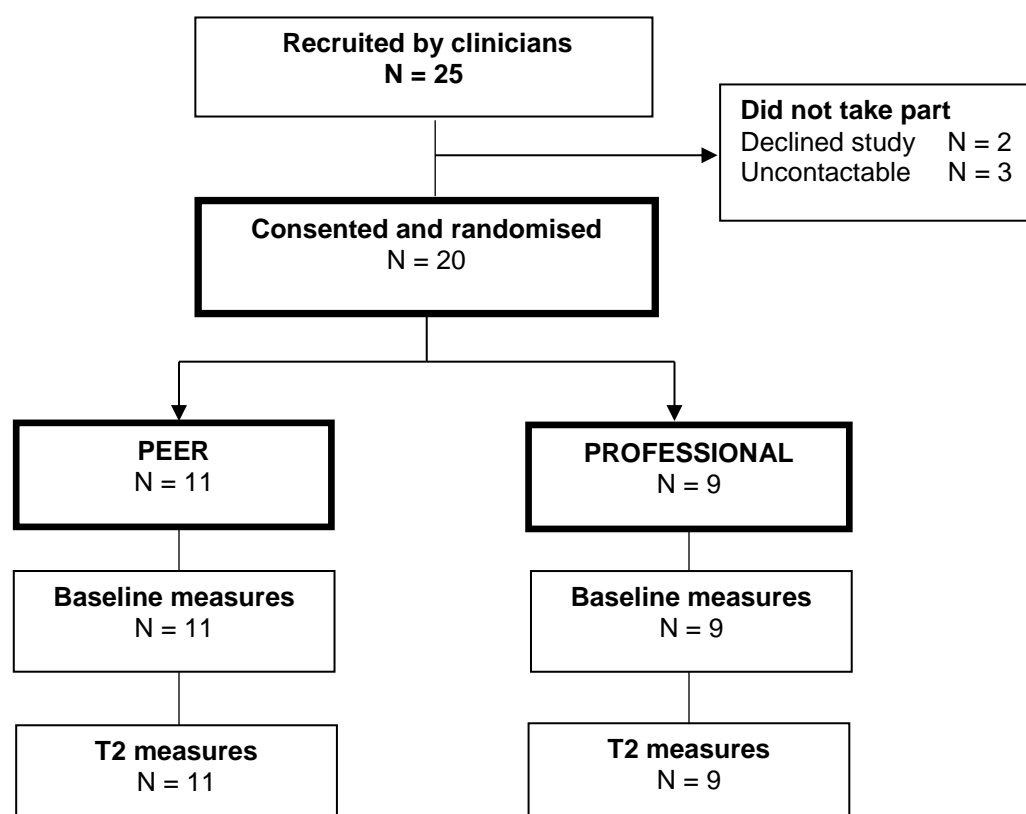


Figure 2 – Consort diagram

Baseline Measures

Table 1 shows the measures collected at time-1 alongside socio-demographic data including: participant's age, gender, ethnicity, education, current substance use, duration of untreated psychosis, time in the EIS and current contact with peers.

Table 1. Baseline measures

Questionnaire	Description	Psychometric properties
Rosenberg self-esteem scale (Rosenberg, 1965)	10 item self-report measure. Responses are rated on a 4-point Likert scale from strongly agree to strongly disagree (0-3). Individual items are summed to give a total score, with higher scores indicating greater self-esteem.	This scale has demonstrated good validity and internal consistency ($\alpha = 0.83$) (Rosenberg, 1965)
New general self-efficacy scale (Chen, Gully, & Eden, 2001)	8 item self-report measure assesses a person's belief in their competence to perform across different situations. Responses are rated on a 5-point Likert scale from strongly disagree to strongly agree (1-5). Individual items are summed to give a total score, with higher numbers indicating greater self-efficacy.	Internal consistency ranges from $\alpha = 0.85$ -0.90 (Chen et al., 2001).
The Empowerment Scale (Rogers et al., 1997a)	28-item self-report measure assesses personal empowerment including: self-efficacy, perceived power, optimism about/control over the future, community activism, and righteous anger. Responses are rated using a 4-point Likert scale from strongly agree to strongly disagree (1-4). Individual items are summed with lower scores indicating greater empowerment.	This scale demonstrated good internal consistency of 0.85 (Rogers et al., 1997b).
The 'Goals and Success' subscale of the Recovery Assessment Scale – revised (Corrigan et al., 2004)	Five items of the RAS-R measure desire to succeed and ability to meet goals. Responses are rated using a 5-point Likert scale from strongly disagree to strongly agree (1-5) with higher scores indicating greater recovery in this subscale.	

Experimental Measure

- The self-stigma of mental illness scale - short form (Corrigan et al. 2012) - this measure is divided into four subscales representing stigma awareness (e.g., “I think the public believes most persons with mental illness are dangerous.”), agreement (“I think most persons with mental illness are dangerous.”), application (“Because I have a mental illness, I am dangerous.”), and harm to self-esteem (“I currently respect myself less because I am dangerous.”). Responses are rated on a 9-point Likert scale from strongly disagree to strongly agree (1-9). The scale has good internal consistency and concurrent validity (Watson et al., 2007).

Experimental Conditions

The two conditions involved presenting participants with a 15-minute video, delivered either by a peer or health professional. Both the peer and professional were from the same clinical team and could therefore draw on the peer’s experiences of psychosis and recovery as examples in both videos. The video involved an interview by the researcher (CA) with a peer or professional focusing on a biopsychosocial explanation of psychosis, examples of EIS treatment and recovery. Both videos were similar in content and based on a script in order to ensure that differences between the two were likely to be due to the presenter (see Appendix L for interview script). The content of the video was designed in collaboration with a woman with personal experience of psychosis, who also co-created the peer video. The presenter in the professional video was female and of a similar age to reduce the possible impact of these variables.

Randomisation

In order to improve homogeneity between groups a simple randomisation was used, which stratified for age (<25/25 years or older), gender (male/female) and length of time since first contact with EIS (first year/more than one year). To determine the strata, published research and local demographic data were searched and the following proportions were used – 70% male (Birchwood et al., 2014), 30% in first year of EI support (based on local EI demographics), 60% 18-24 years (Kirkbride, Stubbins, & Jones, 2012). Within each strata participants were randomly allocated to one of two conditions using a 50:50 ratio. Participants were randomised before completing the baseline measures.

Procedure

Eligible participants were invited to participate in the study by their care-coordinator or by CA during a recovery group session. At this point, participants were briefly informed of what the study involved and received an information sheet. If individuals were interested in participating they informed their care-coordinator or contacted CA directly. CA called those who were interested and arranged a time to meet for the experiment. Prior to completing measures, CA reviewed the information sheet and obtained informed consent. Participants then completed baseline measures before watching the video. Immediately after this, participants completed the post-experiment self-stigma measure and were asked for feedback on the video (see Appendix M). The session lasted approximately 30 minutes and participants were reimbursed for their time.

Analysis

Power. There was no known effect size for the impact of peer support on self-stigma, however, a study that examined brief interventions to challenge stigma attitudes (Campbell, Shryane, Byrne, & Morrison, 2011) reported a medium effect size of (0.3). Based on these findings a power calculation was conducted with a power of 0.8 and alpha of 0.5, for a medium effect size g *power suggests a sample size of 68. The study aimed to recruit a sample of 70 with 35 in each group. This was consistent with studies that used similar designs (Brown et al., 2010; French et al., 2010; Penn, Chamberlin, & Mueser, 2003;), and statistical advice was sought prior to this calculation.

Statistical analysis. Due to the small sample and the number of outliers in the data the proposed statistical analysis was altered (see Appendix N) and non-parametric tests were chosen for the all three hypotheses. The following tests were used:

- Hypothesis 1 - Change scores were calculated by subtracting time-1 self-stigma subscale totals from time-2 self-stigma subscale scores. Mann-Witney U tests were then used to compare change scores for stigma agreement and application between groups.
- Hypothesis 2 – A Wilcoxon signed rank test was used, comparing stigma awareness scores at time-1 with time-2 for the whole sample.
- Hypothesis 3 – A Spearman's correlation was used to assess the relationship between self-stigma subscales and the goal and success measure. If these

variables were found to be significantly related, partial correlations would have been used to test mediating effects of self-efficacy, empowerment and self-esteem.

Prior to analysis, descriptive statistics were summarised and a series of independent t-tests and Mann-Witney U tests were used to examine differences between the two groups in terms of baseline variables.

Missing data. If less than 10% of items within a measure were missed, missing values were imputed with the median for that item (McKnight & McKnight, 2007); questionnaire totals were then generated including the new value. If more than 10% of items were missing the case was excluded from analysis.

Qualitative feedback

Qualitative data were analysed using thematic analysis as its flexible approach allowed the small amount of data to be analysed for themes (Braun & Clarke, 2006). Consistent with Braun and Clarke (2006) guidance, several decisions were made before analysing the data. It was decided that the analysis would be deductive as the responses linked closely to the questions and would focus on a detailed account of one aspect of the data, namely what was helpful about the videos. Themes were coded at a semantic level and an essentialist approach was taken, both of these decisions allowed the reality of participants' experiences to be reflected and examined for meanings (Braun & Clarke, 2006).

Data from the qualitative feedback was read by CA and initial codes were generated in relation to the question 'what was most useful about the video you just watched?'. Codes were then organised into preliminary themes, which were refined over repeated reading of the dataset and comparison between themes. Some of the initial themes were collapsed into broader themes and a thematic map was created. Simultaneously the dataset was analysed by an independent researcher who identified similar themes and one additional theme 'challenging stigma' which was integrated into the final thematic map (See appendix O).

Results

Participant Characteristics

The sample of 20 participants included 12 men (60%) and 8 women (40%), the majority of whom were White British (74%). Participants' ages ranged between 18 and 32 years old, with an average age of 24.15 years ($SD = 4.52$). Participants had an average of 15.5 years education and had been working with the EIS for an average of 20 months. There were no significant differences between the groups in each condition (peer and professional) on any demographic or clinical variables at baseline (see Tables 2 and 3).

Table 2.The socio-demographic data at baseline (N = 20)

	Total sample N= 20		Peer Group n = 11		Professional Group n = 9		
	Mean Median N	(SD) [IQR] %	Mean Median N	(SD) [IQR] %	Mean Median N	(SD) [IQR] %	Test statistic
Demographics							
Age, <i>years</i>	24.2	(4.52)	24.4	(4.65)	23.9	(4.62)	t (18) = 0.23, p = 0.82
Male	12	(60%)	7	(63.6%)	5	(55.6%)	X ² (1) = 0.14, p = 0.71
General education, <i>years</i>	16.0	(3.85)	14.9	(3.41)	14.9	(3.41)	t (18) = 0.68, p = 0.51
Ethnicity							
White	14	(74%)	7	(70%)	7	(78%)	X ² (1) = 0.28, p = 0.60
Other	5	(26%)	3	(30%)	2	(22%)	
Substance use, <i>yes</i>	2	(10%)	0	(0%)	2	(22%)	X ² (1) = 2.72, p = 0.10
Time since first contact with EIS, <i>months</i>	20.0	[12.3-29.5]	21.0	[12.0-28.0]	16.0	[8.5-30.0]	U = 44.50, p = 0.70, r = 0.08
Duration of untreated psychosis, <i>months</i>	1.0	[0.0-2.0]	0.00	[0.0-2.0]	1.0	[1.0-2.0]	U = 28.50, p = 0.09, r = 0.38

Table 3. Clinical outcome data at baseline

	Total sample N= 20		Peer Group n = 11		Professional Group n = 9		Test statistic
	Mean Median N	(SD) [IQR] %	Mean Median N	(SD) [IQR] %	Mean Median N	(SD) [IQR] %	
New self-efficacy scale	27.0	[23.8-33.3]	27.00	[23.0-31.0]	27	[24.0-36.5]	$U = 44.00, p = 0.20, r = 0.10$
Rosenberg self-esteem scale	13.0	[10-18.8]	14.00	[10.0-20.0]	12	[8.0-15.0]	$U = 33.50, p = 0.22, r = 0.27$
Self-stigma of mental illness scale							
- Awareness	28.5	[24.0-33.8]	31.0	[27.0-34.0]	24.0	[15.0-30.5]	$U = 27.50, p = 0.10, r = 0.38$
- Agreement	12.0	[9.3-16.0]	12.0	[9.0-14.0]	11.0	[8.0-21.5]	$U = 48.00, p = 0.94, r = 0.02$
- Application	12.0	[7.0-19.0]	12.5	[6.5-19.3]	11.0	[7.0-18.0]	$U = 42.50, p = 0.84, r = 0.05$
- Harm to self	10.0	[5.0-18.0]	10.0	[5.0-16.3]	10.0	[6.0-23.5]	$U = 37.50, p = 0.54, r = 0.14$
The empowerment scale	58.5	[55.0-65.5]	59.0	[56.0-66.0]	55.0	[47.0-63.0]	$U = 28.50, p = 0.11, r = 0.36$
The goal and success scale	20.0	[18.3-25.0]	20.0	[16.0-25.0]	21.0	[19.5-25.0]	$U = 33.00, p = 0.20, r = 0.29$

Between T1 and T2, those in the peer condition will experience a greater reduction in two aspects of self-stigma (stigma agreement and application) compared with those in the professional condition

A Mann-Witney U test was used to investigate this hypothesis. There was no difference between the peer and professional groups in terms of their change in agreement with stigma ($U = 38.00$, $p = 0.41$, $r = 0.20$). However, there was a significant difference between the groups in terms of change in application of stigma to themselves, with those in the professional condition experiencing a greater reduction in application of stigma between time one and time two compared to those in the peer condition ($U = 14.00$, $p = 0.02$, $r = 0.58$).

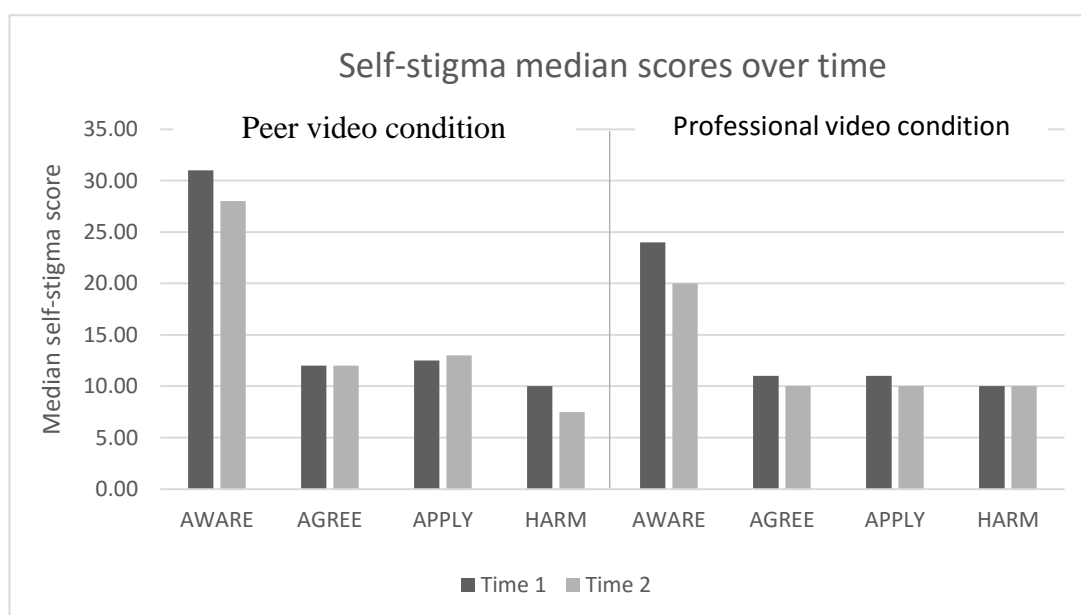


Figure 3. Median self-stigma scores over time

There will be no change in the third aspect of self-stigma (awareness of stigma) in either condition

In both the peer and professional groups, there was no significant difference in awareness of stigma between time one and time two ($Z = -1.91$, $p = 0.06$, $r = 0.43$).

At T1 there will be an association between levels of self-stigma, social mediators and goal directed behaviour

In order to test the final hypothesis, Spearman's correlations were conducted between self-stigma subscales and the goals measure (GAS); see Table 3. There were no significant correlations found between GAS and stigma awareness ($r = -0.39$, $p = 0.09$) agreement ($r = 0.07$, $p = 0.78$) or application to self ($r = -0.37$, $p = 0.12$). As no significant correlations were found no further partial correlations were needed.

Table 4. Spearman's correlation of self-stigma subscales and the goal and success scale

		Awareness	Agreement	Application
Goals and success scale	Correlation Coefficient	-0.39	0.07	-0.37
	Significance (p-value)	0.09	0.78	0.12
	N	20	20	19

Qualitative Feedback

Thematic analysis of the qualitative feedback given by the entire sample, identified three key themes which were: information at the right time, feeling less alone and challenging stigma/increasing hope (See Table 5 and appendix P for full theme table). There were notable differences in themes between the two conditions, with those who saw the professional video reporting the value of information and those who watched the peer video reporting the importance of challenging stigma and instilling hope. Spanning both conditions was the theme of feeling less alone, however, this was spoken about in terms of normalisation by those in the professional condition and shared experiences by those in the peer condition.

Table 5. Themes identified in the peer and professional qualitative data

	Peer condition	Professional condition
Theme 1		Information at the right time
Theme 2 – feeling less alone	Shared experience	Normalising experiences
Theme 3	Challenging stigma and instilling hope	

Information at the right time. One theme identified within the professional dataset was the usefulness of information, particularly in terms of the timing of the information. Participants highlighted that the video was helpful in presenting interesting information, however, there is a sense that the information is only helpful if it is new to the person.

'It was good to have more information about where you can go to get help.'

Participant 15, professional group.

'It's informative for people who don't know what it's about.' Participant 20, professional group.

Feeling less alone. Across both professional and peer conditions there was a theme of feeling less alone and the value of knowing psychosis was a shared experience. In terms of the professional group this was highlighted across almost half of the dataset (4/9). Participants spoke of the importance of hearing that their experiences with psychosis were common and that anyone might develop them under the 'right' conditions.

'Realising that the symptoms were common because they have felt quite alien at times.' Participant 11, professional group.

Within the peer group, this theme was present in the majority of responses (7/11). Participants spoke about the importance of being able to relate to what the peer was saying, the power of hearing from someone who has experienced psychosis and how this could help people to feel less alone.

'I can relate to what she was saying about how she feels even better than before. I feel more equipped for life having experienced psychosis.' Participant 2, peer group.

'Nice to hear the same sort of experiences...you feel less alone.' Participant 13, peer group.

Challenging stigma and giving hope. Amongst several participants in the peer condition there was a theme of empowerment, hope and challenging stigma. Participants commented on how the peer in the video spoke about psychosis in a

normal, non-stigmatising way and how hearing her story helped them to see recovery was possible.

'Nice to see someone succinctly define psychosis in a way that is comfortable and not stigmatising.' Participant 13, peer group.

'Good to see someone who's been through something and is doing well...it gives me hope for the future.' Participant 2, peer group

Discussion

This study aimed was to better understand one of the possible mechanisms by which peer support is effective, namely that people who have experienced psychosis and recovered (peers) may challenge self-stigma in others. Due to the small sample size, the current findings have limited power and therefore firm conclusions cannot be drawn from the data. However, this does not necessarily mean there was no effect and the preliminary findings will be discussed with reference to the evidence base.

Impact of the Psycho-educational Video on Self-stigma (hypotheses 1 and 2)

The findings reveal that there was no significant difference between the two groups in terms of the change in agreement with stigma over time, however, there was a significant difference between groups in the degree to which participants applied stigma to themselves. The direction of this difference was opposite to what was expected, with those in the professional group experiencing the greatest reduction in stigma application over time, compared to those in the peer group. These findings do not support the primary hypothesis and are counter to previous qualitative research, which suggested that peer support can help people to exit the cycle of stigma and challenge stigmatising ideas people may hold (Mowbray, Moxley, & Collins, 1998; Pyle & Morrison, 2014). It is important to note the methodological differences between the current study and previous research as a possible factor contributing to the difference in findings. To the best of the author's knowledge, this is the first experimental study to compare the impact of peer versus professional delivered psycho-education on self-stigma.

Considering the small sample it is important to treat these findings with caution as they may change with increasing statistical power. However, it is also possible that these findings will remain in the data as the sample and power increases and

therefore it is important to consider possible explanations for the difference in stigma application scores. One potential explanation is that psycho-education from a professional has more power to challenge self-stigma due to beliefs about the professional's expertise. Alternatively, hearing the honest reflections of someone who has experienced psychosis may encourage more honesty at the second time point, accounting for the slight increases in some participants' scores of stigma application. Previous research has proposed that authenticity in a role-model can influence authenticity and honesty in others (Gardner, Avolio, Luthans, May, & Walumbwa, 2005). Additionally, it is possible that, whilst some participants identified positively with the peer, others may not have or may have engaged in upward social comparison leading them to feel lesser and therefore not challenging self-stigma. Previous research has found that some people with psychosis do make upward social comparisons, particularly with regards to rationality and their ability to work (Finlay, Dinos, & Lyons, 2001).

With regards to the second hypothesis, the current findings add support to this in showing that there was no significant change in stigma awareness over time in either group. However, there is a trend towards a reduction in awareness of stigma over time in both groups, which may or may not reach significance as the sample size increases. It is possible that this trend is indicative of demand characteristics, with participants believing that their scores should be lower on the second completion of the measure.

Relationships between Variables of 'Why try' Model (hypothesis 3)

Correlational analysis revealed there was no significant relationship between the subscales of self-stigma and the goal and success measure, therefore, components of the 'why try' model could not be tested. This does not support the third hypothesis or the research that has tested this model (Corrigan, Bink, Schmidt, Jones, & Rüsch, 2015). However, the lack of a significant relationship between self-stigma and goals may have been a result of a type 2 error due to the small sample size, i.e., real effects could have been missed. It is also important to note that the goal and success measure assesses perceptions of success in relation to goals, rather than goal directed behaviour itself. Ideally to test this model, goal directed behaviour or engagement with evidence based practices would be more objective measures.

Qualitative Findings

Qualitative findings suggest that the most important theme across both groups was that the videos helped people to feel less alone, however, how this was achieved differed. Those in the professional condition spoke of the advantages of hearing symptoms are common and therefore they are not alone, whereas those in the peer condition spoke about the importance of relating to the peer and how this helped them to feel less alone. The groups also differed in terms of the other themes highlighted, with those in the professional condition discussing the importance of information and those in the peer condition discussing the importance of speaking about psychosis without stigma and instilling hope. These themes echo the results of the earlier literature review, which found that the key components of peer led interventions for internalised stigma split into the more generic (professional) components of information and problem-solving, and the more unique peer components of shared experience and developing non-stigmatising narratives. These qualitative findings support previous research, which suggested that peers can increase an individual's sense of hope and empowerment (Davidson et al., 2006) and help people to feel better understood and accepted (Sells et. al., 2006). Further research is needed, however, to investigate whether hope and empowerment underpin peer support.

Limitations and Improvements

One of the main limitations of this study is the small sample size. As a result of this, the analysis is statistically underpowered and there is increased likelihood that the significant findings of this study may be due to chance. Additionally, small samples are known to increase the probability of missing significant effects that would be present in a larger sample (Haslam & McGarty, 2003). The small sample also reduces the likelihood of it being representative and consequently limits the degree to which any findings can be generalised.

Secondly the study is limited in terms of its design as it did not include a neutral video condition. A neutral video would have helped to determine whether self-stigma would change over time regardless of psycho-education. As previous research had shown psycho-education by a professional can reduce stigmatising ideas in non-clinical populations (French et al., 2011), there may not have been a large enough difference between the two groups to see an effect.

Finally, it is important to consider that this study may have been limited in using female presenters in a sample that is proportionally more male. Research into mentoring in educational settings has found that identification with positive role models can be influenced by whether or not the role model is gender matched (Lockwood, 2006). With a larger sample size it would be useful to test whether gender had influenced the findings, particularly in the peer condition.

Further Research

Future research is needed to test different theories for peer support. The qualitative findings of this study suggest the importance of hope and not feeling alone, research is needed to test these variables, perhaps comparing hope in those who receive peer support from someone with lived experience against a support from a worker without this. Research is also needed to explore how and when peer support is most effective. The participants in this study had been working with the EIS for an average of 1 year and 8 months at the time of taking part in the research. It is possible that peer support may be more effective early on in an individual's journey through EIS, however, unfortunately this is not possible to examine in the current dataset. Finally, if the findings of this study continue to show that professionals have the greatest impact on self-stigma it would be useful to investigate how brief psycho-education by a professional could be used on a larger scale to reduce self-stigma.

Conclusion

Overall, it is not possible to draw conclusions from the current findings and more data are needed to better understand the impact of both psycho-educational videos on self-stigma. However, the preliminary findings suggest psycho-education by a professional may reduce aspects of self-stigma and that receiving peer led psycho-education can help individuals to feel less alone and more hopeful. As theory behind peer support suggests it has the potential to undo the damage of stigmatised diagnoses (Mead et al., 2001), it is essential that research continues to investigate the active ingredients of peer support. Having a better understanding of how peer support is effective would allow researchers and clinicians to then establish for whom it is most effective, in what format and whether it should be offered at a particular point in an individual's journey.

The key take home messages from this study are that psycho-education, delivered by either a peer or professional, was viewed by participants as an acceptable format. Additionally qualitative feedback of participants suggests that, beyond the normalising

and informative benefits of psycho-education by a professional, peers have unique benefits in challenging stigma, instilling hope and helping young people feel less alone in their experiences. Another key message from this study is that, though the theoretical basis for peer support is still developing, there seems to be some value in Social Identity Theory as a way of understanding what underpins the positive effects of peer support. Further research is needed to examine this, however, SIT seems to echo the qualitative findings of this study; the idea that peers uniquely challenge self-stigma through offering a connection to the in-group and promoting a more positive sense of shared identity.

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Executive Summary

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An experimental study to investigate the impact of a psycho-educational video delivered either by a peer or a professional on self-stigmatising attitudes in first episode psychosis

Why the study was conducted

Psychosis is a stigmatised mental health condition and people who experience it are often subjected to negative stereotypes such as being dangerous, incompetent or unable to recover. Internalising these stereotypes (self-stigma) can damage an individual's identity and belief in their own abilities, which can in turn lead to poorer recovery outcomes such as: poorer engagement with health services; lower quality of life and difficulties pursuing employment.

Peer support has been shown to impact positively on recovery and theory suggests that this may be achieved through challenging stigmatising attitudes and instilling hope. A peer is someone who has personal experience of psychosis and is at a later stage in their recovery process. Whilst there is evidence suggesting peer support is effective, the reason why it is effective is less well known. The aim of this study is to investigate one possible way in which peer support may be effective i.e. the impact of peers on challenging self-stigma in others.

What the study involved

Between August 2015 and May 2016, 20 participants from Early Intervention in Psychosis teams took part in this research study; the study had initially aimed to recruit 70 participants. Participants who took part in the study were asked complete a self-stigma questionnaire before and after watching a 15 minute psycho-educational video, delivered either by a peer or a health professional. The choice of video was decided at random and both videos were similar in content and based on a script in order to ensure that any differences between the two were likely to be due to the presenter (peer or professional). The primary research question was to determine whether those in the peer group would experience a greater reduction in self-stigma scores than those in professional group after watching the video.

What the study found

The study experienced difficulties with recruiting participants and so the study findings must be treated with caution until further data is gathered. The current findings show that there was no difference between the two groups (peer and

professional) in terms of one component of self-stigma (agreement with stereotypes) but there was a significant difference between groups in another component (application of stigma). However, this difference was not in the expected direction as those in the professional group experienced the greatest reduction in stigma application over time, compared to those in the peer group. These findings do not support the primary hypothesis and are counter to previous research, which has found that peer support can help people to exit the cycle of stigma and challenge stigmatising ideas people may hold. Verbal feedback from participants in the peer group highlighted the importance of being able to relate to the peer in the video and how that helped them to feel less alone and more hopeful.

What were the limitations?

This study had several limitations which may have impacted on the findings. One of the main limitations of this study was the small sample size, which meant that the study was statistically underpowered and therefore the accuracy of the findings cannot be determined. Secondly the study was limited in its design as it did not include a neutral video and therefore it is not possible to know whether self-stigma would have changed over time regardless of psycho-education. Finally the study is limited in terms of its simplicity because if there is a relationship between peer support and self-stigma it is likely that this relationship is complex and may not be captured by experimental design. Further research is needed to address these limitations and to better understand peer support.

Research Connecting Narrative

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Connecting narrative

One aspect that drew me to Clinical Psychology training at Bath was the emphasis on producing a portfolio of publishable research studies, rather than a single thesis. I hoped this would allow me to develop my research interests and encourage me to continue with research beyond the course. Prior to training, much of my experience had been within academic research and I was keen to continue to develop my research skills further. I also recognised early into my training the significant gap between the research and clinical worlds and was keen to learn how to integrate research into clinical practice. Through this narrative, I will reflect on each piece of research I have completed during the course and what I have learnt as a result of these experiences.

Service improvement project

Developing an idea

The initial idea for my service improvement project came from Jackie MacCallam, a Clinical Psychologist embedded within a respiratory team at a local hospital. Jackie was keen for research to investigate how to enhance the psychological input into her team and she was particularly interested how patients experienced one of their most invasive procedures – the cardiac catheter (CATH). This idea was presented as part of the research fair in the first year and myself and colleague, Cara Roberts-Collins approached Jackie to discuss ideas.

Through our discussions we decided to design two parallel qualitative projects exploring patient and staff experiences of the CATH procedure. Luckily Cara was keen to conduct the project with staff and I was more drawn to the project with patients. In designing this project, we were influenced by a paper we were reviewing for the course at the time, which explored positive adjustment to visible difference. We decided we would explore positive coping with the CATH procedure as a way of better understanding what helps people manage the procedure psychologically and how we could enhance that for other patients.

Process of research

Cara and I collaborated initially to develop our parallel interview structures, which were guided by the self-regulation model and so followed a clear structure. I enjoyed this process and found it useful working in a team as we could practice the interview procedure on each other and think about how the questions sounded and fitted

together. I then sought ethical approval from the university and the research and development department at the hospital, both of whom passed the study with few amendments.

The experience of recruitment for this study was wholly positive. Of the 19 invitations sent out 12 replied and said they would be happy to take part in a research interview. This exceeded my expectations of recruiting participants via letters and I have since reflected on what may have influenced this positive response. One factor that seemed to be important was that the consultants from the respiratory team were very engaged in the project and offered to send out an initial invite letter informing patients of our study. From meeting with the participants, I got a sense that most had a very good relationship with the respiratory team and thought very highly of the consultants within the team.

Through this project I had the opportunity to travel around and meet with ten people who had been through this invasive procedure and who had often faced several other challenges to their health. Conducting qualitative interviews allowed me the freedom to hear each person's story and guide the interview in a natural way. Hearing each person's experience, particularly focusing on their strengths and coping, reminded me of how resilient people can be. I was inspired to hear how people had found meaning in the most painful, difficult experiences they had with their health and how they had managed to continue with what was important to them in life. Speaking about the CATH procedure also reminded me of the importance of every interaction within a healthcare system and how these all impact on how supported someone feels.

Challenges and personal learning

Whilst much of my experience of collaborating on this project has been very positive, it has also challenged me at times. I particularly found it difficult to synchronise my deadlines with Cara as my data collection took slightly longer and I had a naturally slower pace of working. At times I found myself making unhelpful comparisons in terms of progress and struggling with my feelings around this. Thankfully I have felt able to discuss this with Cara and we negotiated our deadlines and how to manage as a team. Whilst making unhelpful comparisons is something I was aware of within myself, working on this project helped to build my confidence to discuss my insecurities and seek support when I needed it.

Contribution to clinical practice

I was really pleased with the response of the respiratory team to our findings and their enthusiasm to put our recommendations into practice. Through the project we developed a leaflet and patient passport, both of which the team planned to use. We also suggested the idea of creating a video in addition to the leaflet and the team were very receptive to this and discussed options for obtaining funding to take this idea forward. Working with such an enthusiastic, receptive team was a really positive experience for me. I was impressed that, even in such a medical setting, there was a real commitment from the health professionals to the psychological wellbeing of their patients and I admired their openness to new ideas. The team's enthusiasm, commitment and openness are values I hope to cultivate within myself and take into my clinical work in future.

Main research project

Study development

My initial interest in internalised stigma came from my experience, prior to training, of support work within secondary mental health services. Through working with one man particularly, I observed that it was not his symptoms which had the greatest negative impact on his life, rather it was the impact of a diagnostic label – treatment resistant schizophrenia. Working with this man over a year taught me how powerful diagnoses can be and how the stigma intertwined with certain diagnoses can begin to become part of how someone defines themselves.

My interest in internalised stigma was further developed through my clinical work on this course and after a lecture on stigma I decided to approach Lorna to discuss the possibility of conducting a literature review in the area. Through discussions, we also came up with several ideas for main projects and I decided to complete my MRP in this area as well. My initial idea was to explore the impact of internalised stigma on engagement in young people with psychosis; however, as I developed the proposal for this idea I found that numerous factors complicated the relationship I wanted to investigate.

Over discussions with my supervisors, I decided instead to investigate whether one of the mechanisms by which peer support is effective is that peers reduce internalised stigma. We decided to design a simple experimental study which would investigate a small part of why peer support may have benefits for young people with psychosis.

Once the proposal was passed we applied and obtained ethical approval for the study.

Creating the videos

My study design involved creating two psycho-educational videos, the prospect of which I found very daunting having never been involved in a project like this before. To design the videos I researched other psycho-educational videos made by EI teams and met with a woman with personal experience of psychosis, Nel, who spoke to me about her story. I drafted interview questions based my meeting with Nel and on previous videos and then Nel kindly checked these through before we finalised them. I was also helped by an Occupational Therapist of a local EI service (Becky) to make the professional video. I am very grateful to both of these women and to Simon Wharf (Audio-visual technician) who helped us feel comfortable and shot the video beautifully. On reflection, I thoroughly enjoyed the process of making these videos and felt added a therapeutic element to the research.

Challenges

The process of recruitment for this study has been quite challenging. Whilst the eight recruiting teams all responded very enthusiastically to the research, the experience of recruitment itself was very slow. To try to improve recruitment I took several steps including: identifying the barriers to recruitment, collaborating with another colleague (Emma Stephens) and offering joint research sessions, keeping in regular contact with teams and attending team meetings where possible. Through discussions with clinicians, it seemed the main barriers to recruitment were competing demands (both clinically and with research) and recent changes within the service. Additionally to the above amendments, Emma and I amended our studies to allow us to directly recruit through recovery groups, this proved successful in encouraging a couple of service users to want to take part.

The second big challenge for me came when I analysed my findings and discovered an effect in the opposite direction to which I expected i.e. the professional video produced a greater reduction in internalised stigma than the peer video. Whilst I was aware that this was likely to be a chance finding due to my small sample size, I found myself checking and re-checking the data and analysis in a way that I might not have had I found what I expected to. This process highlighted to me that I had my own biases. I had been drawn to this area of research because intuitively I thought peer

support would impact positively on internalised stigma, however, I hadn't prepared myself for that fact that, in doing this research, I could potentially find the opposite.

Personal learning

I have been really encouraged by the response of other people to this research. From my ethics committee meeting, to meeting with EI teams and meeting with my participants, I have been greeted with a positive response and a sense that this research is worthwhile and timely. I have really enjoyed meeting with participants and particularly hearing their responses to the Nel's story and their connection with that. On reflection, I think including more of a qualitative element to this study would have been valuable to really capture my participants' reactions to the videos and their own stories of recovery and hope.

Whilst this is not new information to me, conducting this research project has reiterated to me the value of conducting research in groups. I could not have completed this project without the invaluable input of Nel, Becky and Simon, equally I don't think I would have managed the struggles of recruitment without my colleague Emma and my supervisors. Collaborating with Emma on recruitment allowed us to spread our resources, problem solve together and to support each other with the various complications and frustrations. Thanks to all that have contributed to this project, I have never felt alone and I am so grateful for having people with different perspectives and skills around me. I believe this input has made my project stronger.

Contribution to clinical practice

As yet, this study has an underpowered sample size and thus its contribution to research and clinical practice is limited, however, I hope to continue recruitment beyond viva to maximise my sample size before publication. Potentially this study could help us to better understand peer support and add to the evidence for its effectiveness. It also has the potential to show how a very low intensity intervention could impact on self-stigma. In terms of my own clinical practice I think this project has contributed significantly. Hearing Nel's story was very inspiring and helped me to see how people can grow through experiencing psychosis and go on to experience a more fulfilling life.

Literature review

Developing an idea

The idea for my literature review was developed through discussions with my supervisors, Lorna and Emma, about conducting a review of ? interventions for internalised stigma in mental health. Lorna had noticed that there was an increasing amount of literature being published on different peer and clinician-led interventions for internalised stigma and thought it would be helpful to draw together the key components of these. I felt this was a really valuable area of research and decided to submit a proposal to review peer and therapist led interventions to improve self-stigma

Unfortunately, between the writing of this proposal and commencing the project in my second year, a very similar literature review was published and I needed to rethink my idea. With the help of my supervisors, I explored different options within the same field. This process was quite time consuming as each idea needed to be developed and the literature briefly searched before I could determine whether it was a viable literature review. After a couple of different ideas seemed unfeasible due to insufficient literature or similarity with other reviews, I found a viable project with enough papers to make a review possible. My literature review focused on the impact of peer-led interventions on levels of internalised stigma in health conditions.

Challenges

I found the process of conducting this literature review really difficult at times. I found developing each new idea for a review was an emotional journey as I would invest in the idea and its rationale, and then feel disappointed when I realised the idea was not going to come to fruition. I found myself struggling with the dilemma of whether to stay conducting a review in an area I felt passionate about and, by then, knew quite well or whether to change to a totally different area. Through this time, I was very grateful for the support and encouragement of my supervisors. With each idea I immersed myself in the area and the proposal and my supervisors were able to help me step back and objectively see whether the idea was viable.

Personal learning

This literature review was a steep learning curve for me, having never conducted one previously. I felt there was little guidance on this project from our teaching and it seemed to me that published reviews varied greatly in their style and structure. One skill I feel I have developed over the course of this project is to move between focusing in on the detail of each paper and expanding my focus outward to see patterns between papers and how to draw conclusions from varied studies. I found

this shift in focus required a lot of energy but as I practiced it felt more natural to switch between the two modes.

As a result of my proposed review falling through, I have had the opportunity to read quite broadly in the area of peer support and internalised stigma. My review has taken me beyond mental health to consider how internalised stigma affects various different health conditions and learn about the creative ways people have intervened with stigma around the world. Through my review, I have rediscovered the literature on social identity theory and been influenced by researchers who see stigma as a social injustice and not something to necessarily intervene with through psychological therapy. Through reading this literature and my lectures in final year I have started to become interested in community psychology and hope to further pursue this interest beyond my training.

Case-studies

Completing case-studies on each of my placements has helped me to be aware of the links between my clinical work and the wider theory and evidence base. I have enjoyed having the opportunity to think about one piece of clinical work in depth and the chance to monitor different aspects of change through therapy. Completing two experimental studies has also helped me to learn how to measure progress through therapy and how to better understand which components of therapy have been most effective. On reflection, I would have liked to gather more in depth qualitative information from clients to explore different therapeutic components and how they have been effective.

Through completing five case studies I have learnt about the importance of selecting meaningful measurements of change and have moved from collecting symptom measures to a range of outcomes considered important to the work. I feel the variety within my case-studies reflects some of the varied work I have been able to complete through placements. The varied case-studies have allowed me to explore different aspects of each work e.g. CAMHS behavioural experiments, OA therapeutic relationship and the importance of adapting formulations and interventions.

Overall reflections and ongoing interests

Overall I found the process of juggling several different research projects, with other work commitments, challenging at times. I found that, particularly with my MRP, I

couldn't devote the time I wanted in order to improve recruitment, for example, by attending weekly meetings in every team. I have felt that I have had to spread myself quite thinly at times in order to meet the course requirements. However, through research on this course I have gained further confidence in my ability to take a study from design to write-up, skills in how to conduct a literature review and the chance to develop an area of interest in terms of research.

I am leaving the course after three years with the same belief I had at the start of the course, that research is integral to good clinical practice. However, I feel I have gained a better understanding how difficult real clinical research can be and how to critique published research. I would like to remain involved in research and am considering the possibility of working part time in research and part time in clinical practice. Ideally I would like to develop my skills as a qualitative researcher and remain involved in research that seeks to understand how we challenge mental health stigma. If I work full time in the NHS, I would like to work in a service that thinks about what it does and always tries to improve that, not because they are told to but because they care. I would like to be involved in evaluating the services I deliver and working in collaboration with service users and colleagues.

Acknowledgements

I would like to thank all of those who have inspired, supported and encouraged me throughout the Doctorate in Clinical Psychology.

Research

In terms of research experience through the course, I would like to thank my supervisors – Andrew Medley, Cathy Randle-Phillips, Emma Griffith and Lorna Hogg for their guidance and support. Those who helped me to create the videos for my main project, including the presenters and Simon Wharf (Audio and Visual Department). I would also like to thank all of my research participants for giving up their time and sharing their experiences with me.

Placement supervisors

I am very grateful to my placement supervisors for their inspiration, support and encouragement over the past three years. I have struggled to find where I fit over the last three years but my supervisors have generally been reassuring and encouraging me that I can be a psychologist and be myself. Thank you particularly to Jim Nightingale, Nick Benians, Claire Cheswick, Katie Baughan, Kate Chapman and Stu Brooke.

To all of the people I've seen for therapy, I am grateful for their understanding and patience with me. I have learned from each person I've worked with.

Family and friends

I could not have made it through the last three years without the support of my family and friends. Thank you for believing in me, supporting me, helping me keep perspective and for being there at the other end of the phone. Thank you as well to my cohort for helping us stick together.

Thank you all.

Appendices

Catriona Anderson

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May 2016

Appendix A- Author guidelines for Literature Review

CLINICAL PSYCHOLOGY REVIEW

Journal Aims

Clinical Psychology Review publishes substantive reviews of topics germane to clinical psychology. Papers cover diverse issues including: psychopathology, psychotherapy, behavior therapy, cognition and cognitive therapies, behavioral medicine, community mental health, assessment, and child development. Papers should be cutting edge and advance the science and/or practice of clinical psychology. Reviews on other topics, such as psychophysiology, learning therapy, experimental psychopathology, and social psychology often appear if they have a clear relationship to research or practice in clinical psychology. Integrative literature reviews and summary reports of innovative ongoing clinical research programs are also sometimes published. Reports on individual research studies and theoretical treatises or clinical guides without an empirical base are not appropriate.

Outline of page requirements

Manuscripts should ordinarily not exceed 50 pages, including references and tabular material. Exceptions may be made with prior approval of the Editor in Chief. Manuscript length can often be managed through the judicious use of appendices. In general the References section should be limited to citations actually discussed in the text. References to articles solely included in meta-analyses should be included in an appendix, which will appear in the on line version of the paper but not in the print copy. Similarly, extensive Tables describing study characteristics, containing material published elsewhere, or presenting formulas and other technical material should also be included in an appendix. Authors can direct readers to the appendices in appropriate places in the text.

Appendix B – Author guidelines for Service Improvement Project

Social Science and Medicine

Journal Aims

Social Science & Medicine provides an international and interdisciplinary forum for the dissemination of **social science** research on **health**. We publish original research articles (both empirical and theoretical), reviews, position papers and commentaries on health issues, to inform current research, policy and practice in all areas of common interest to social scientists, health practitioners, and policy makers. The journal publishes material relevant to any aspect of health from a wide range of social science disciplines (anthropology, economics, epidemiology, geography, policy, psychology, and sociology), and material relevant to the social sciences from any of the professions concerned with physical and mental health, health care, **clinical practice**, and **health policy** and organization. We encourage material which is of general interest to an international readership.

Outline of page requirements

Peer-reviewed original research articles and critical or analytical reviews in any area of social science research relevant to health. These papers may be up to 8,000 words including abstract, tables, and references as well as the main text. Papers below this limit are preferred.

Appendix C – University Ethical Approval for Service Improvement Project

Dear Cate

Reference Number 14-154

Thank you for satisfactorily attending to the queries raised by the committee. I can now confirm that you have full ethical approval for your study.

Best wishes with your research.

Dr Helen Lucey
Chair Psychology Ethics Committee
University of Bath

Information about making an ethics application can be found at
<http://moodle.bath.ac.uk/course/view.php?id=52192>

On 24/07/2014 08:07, ca469@bath.ac.uk wrote:

> Dear Helen,
>
> Please find below the forwarded message from Sarah Kitching confirming
> that the project is registered with her as an audit.
>
> Best wishes,
> Cate
> _____
> From: Kitching Sarah (ROYAL UNITED HOSPITAL BATH NHS TRUST - RD1)
> Sent: 23 July 2014 14:20
> To: Anderson Catriona (AVON AND WILTSHIRE MENTAL HEALTH PARTNERSHIP NHS
> TRUST)
> Subject: RE: Service improvement project
>
> Dear Cate
>
> Thank you for your completed proposal form. I confirm that your project
> has been accepted and registered on the Trust audit database as ID 2385.
>
> With best wishes
> Sarah
>
> Sarah Kitching
> Quality Improvement Lead for Medicine
> Quality Improvement
> Qulturum - D1
> Royal United Hospital Bath NHS Trust
> Combe Park
> Bath BA1 3NG

Appendix D – SIP Interview Schedule

Beliefs and decision-making about the procedure and coherence:

Can you tell me a bit about how you found out that you needed the procedure?
When /Who told you/where?

How did you feel when you first found out?

Can you tell me why the CATH procedure was recommended for you? What helped you to make decisions about undertaking the procedure?

How well do you understand the procedure?

What do you understand about the risks in undertaking the procedure? How did the risks impact on you?

And what do you believe the benefits of the procedure to be?

Perceived control, coping and self-management skills:

How confident and in control did you feel thinking about and preparing to undertake the procedure?

What strategies have you used to help you cope before, during and after the procedure?

What do others do that you have found helpful/not so helpful in terms of preparing for, undertaking the procedure?

What's the one question you wished you were asked, or one piece of advice that might particularly help?

Consequences (Physical, psychological, social, economic)

How does the procedure affect you in everyday life?
(What you can do/what you can't do. How does it make you feel that you can/can't do that?)

How did you get through the procedure? What helped you manage/cope?

Are there other people who help you to manage?
Family, carers, health professionals, friends

What have other people done to help you? What support have you received?
Practical help/ emotional support, what was helpful in supporting you/patient?

How does it feel to have other people helping to look after you?

Illness identity

Can you describe the physical symptoms and effects that the procedure causes?
How difficult do you find these symptoms to manage?

Emotional representations

How much does the procedure affect you emotionally?

Timeline

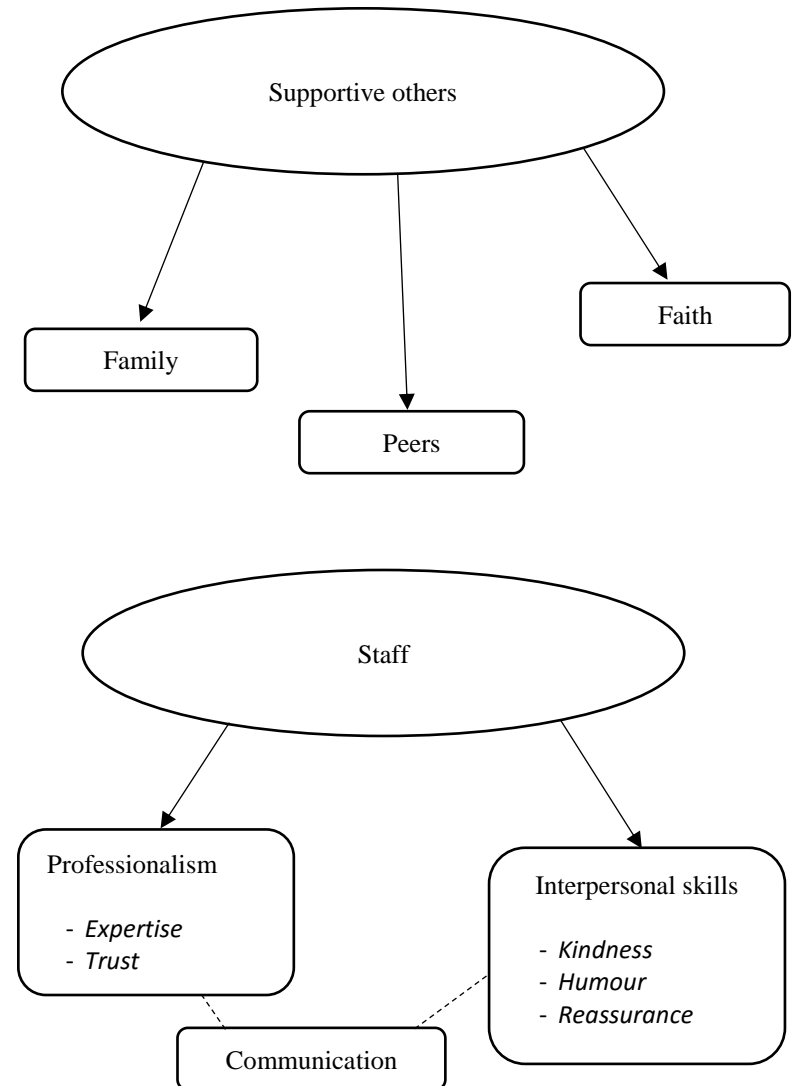
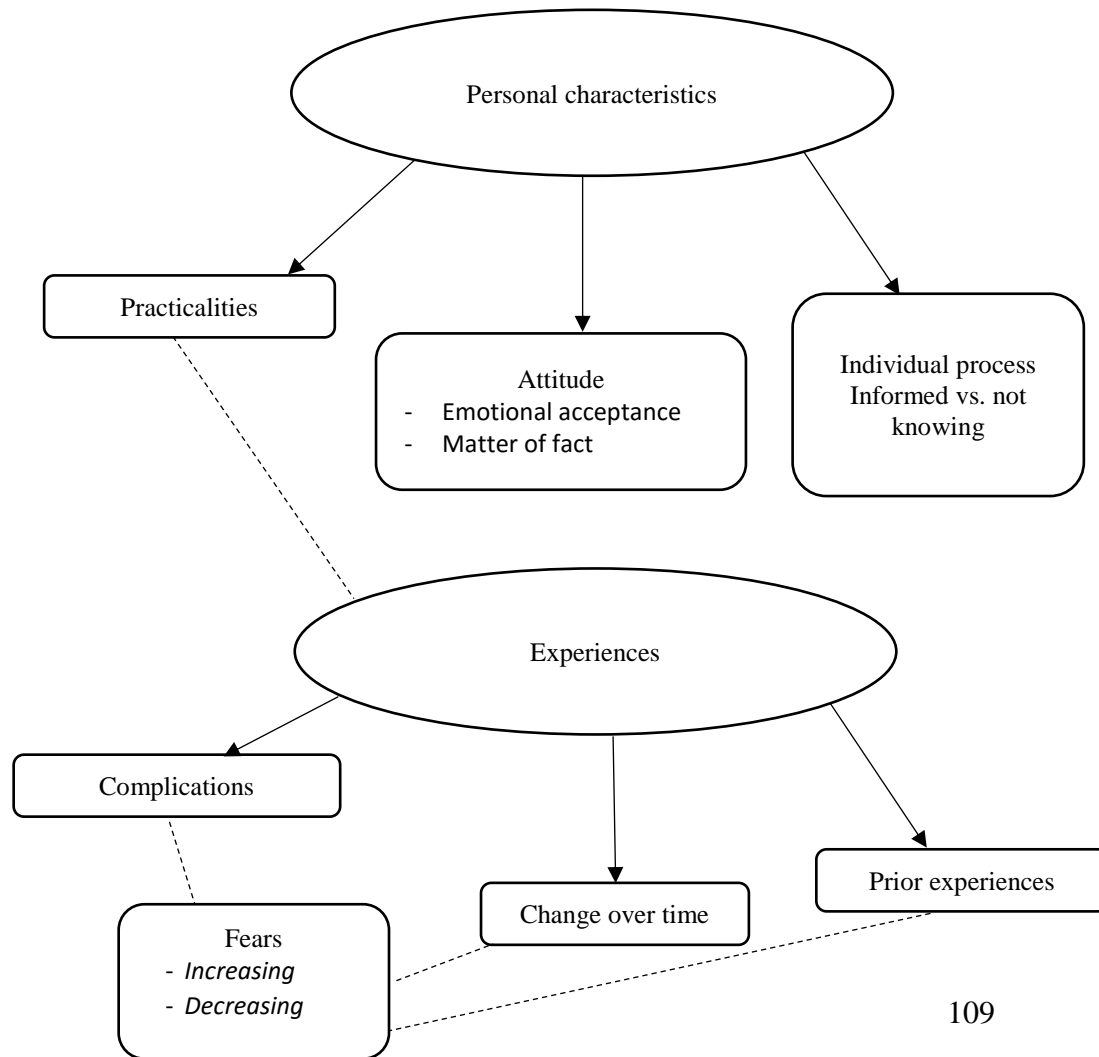
Has your perception of the procedure changed over time? *Does it go up and down / Do you feel it is getting easier or harder to manage?*

What do you think will happen in the future? *Will it stay the same / change. Do you think anything else will happen in the future because of the procedure?*

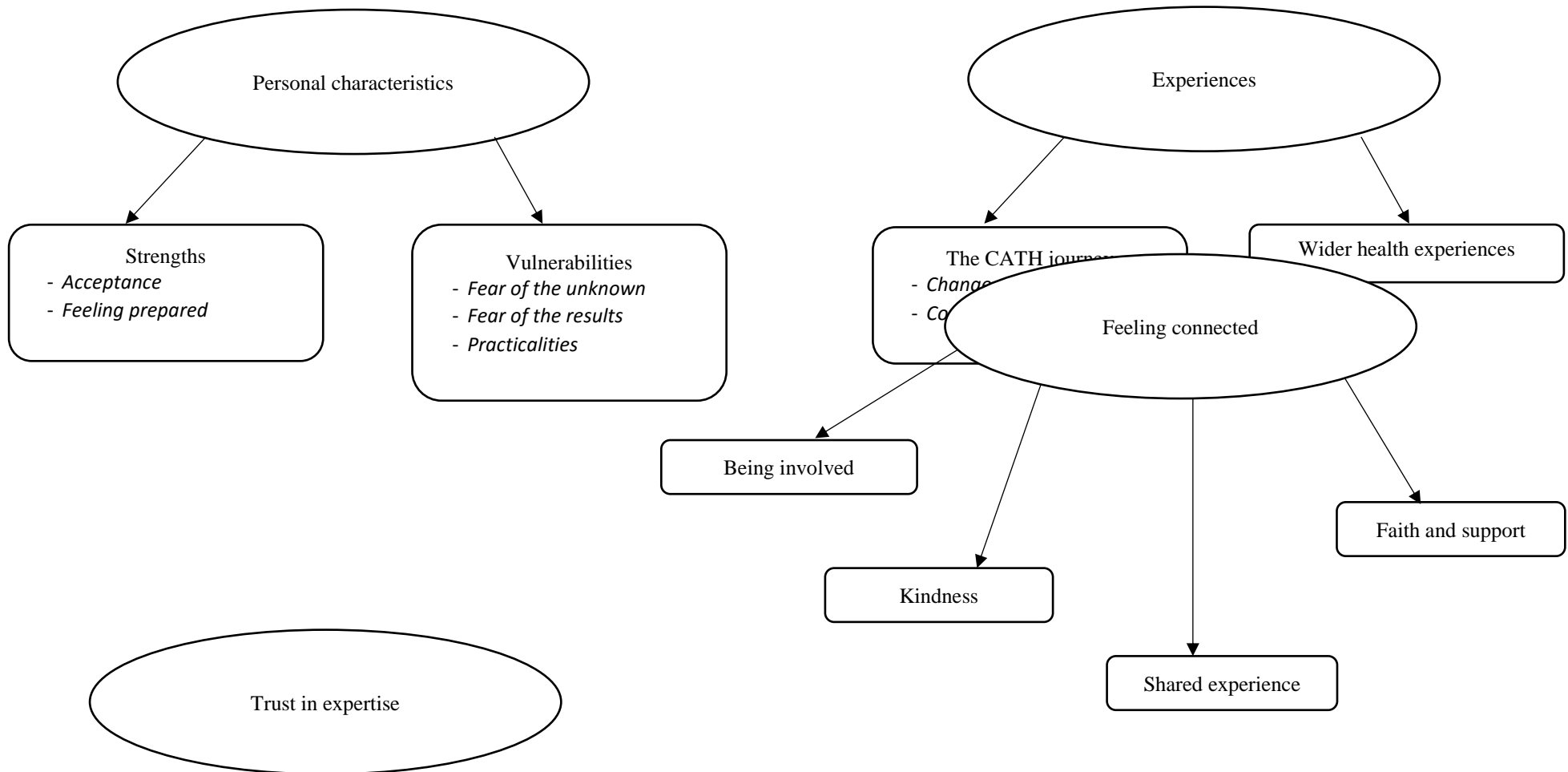
Is there anything else that you would like to tell me about that I have missed?

Appendix E - SIP Thematic maps

Initial thematic map



Final thematic map



Appendix F – SIP table of themes and quotes

Superordinate theme	Subordinate theme	Quotes
Individual process	Strengths - Acceptance	<p><i>Well I try not to worry...I try not the think about it to be honest...but it's part of the process I guess really to have one...just to see what's going on (Interview 1)</i></p> <p><i>Erm...I wasn't bothered...I was quite...it was a case of that's the programme for tomorrow and we're going to do it and that was it...just sort of took it in that frame of mind...I wasn't panicking on anything like that. (Interview 3)</i></p> <p><i>...I'm not the sort of person who likes to be fussed around you know I just think get your head down and get on with it...(interview 10)</i></p> <p><i>No not really I mean for me I thought it was just a very simple straight forward job you just wait your turn...there were other people in front of me sort of thing and err...just wait your turn there's nothing to it really...(Interview 4)</i></p> <p><i>but I mean going back to how you feel it's facing your demons really rather than it being lurking like will I get it? won't I get it? (Interview 2)</i></p>
	- Being informed	<p><i>I think well they did talk to me and talk me through it all first so I knew what was going on and that was definitely helpful because then I knew that ok this is what they're doing...(interview 7)</i></p> <p><i>Yes I mean some people don't want to know but I'm one of those people who do like to know because you are best able to deal with it and I think that helps you get over the initial...fears or anxieties about it...(Interview 5)</i></p> <p><i>Fully in control I think I mean they explained exactly what you needed to do and what you needed to do and when you needed to be there so that was fine...(interview 8)</i></p>

		<i>it's nice to read like a programme then before you have it done...you know then can explain it but when it's written down on paper you can sort of go with it (interview 1)</i>
Individual process	Vulnerabilities - Fear of the unknown	<p><i>I knew more or less what to expect it's just that little bit of nervousness before you go in to have the procedure because although it's explained you still don't know how you're going to react when you actually go in to have the procedure done (Interview 5)</i></p> <p><i>Yes (I was feeling apprehensive) because when you have something done for the first time it's like oh my god you know...(Interview 9)</i></p> <p><i>Um so I suppose the first time is a bit more of a worry because you're not quite sure what you're going into behind those double doors...(Interview 2)</i></p>
	- Fear of the results	<p><i>Um well yeah it's just fear of the unknown really isn't it and didn't know what's happening but you know you're going to get a result one way or the other so I was quite panicky... (Interview 10)</i></p> <p><i>I mean one's always a little bit apprehensive about the results and hoping they're going to be what the doctors want them to be...(Interview 9)</i></p> <p><i>I think it's probably going to be the same going into future ones because I think the worry's always going to be – have I got worse? Have I got better? Are they going to increase the medication? Are they going to take me off the medication? Yeah things like that... (Interview 7)</i></p>
	- Worry about practicalities	<p><i>...if I had to have the stress of driving into <place name> from here and getting into the disabled carpark you know can be a nightmare...and then that would have added to the stresses and strains but I don't have to do that, which does make a difference...(Interview 9)</i></p> <p><i>They forget you're suffering with breathing problems and you have to walk miles to get to each place...and the car parks that's the biggest problem of all (Interview 6)</i></p>

		<p><i>no but it was really a lot of unnecessary waiting around I thought, that was my big experience of it...but the actual catheterisation itself was no problem (Interview 6)</i></p> <p><i>...that's the worst part of it is getting down to <place name> and the parking – things not associated with any Catheterisation...(Interview 4)</i></p> <p><i>...the worst part of it all the catheterisation and that is getting to <place name> and back and when I get back I'm shattered and is it worth it? (Interview 4)</i></p>
Experience	- The CATH journey	<p><i>Well the first one definitely not obviously because it was an emergency it was like woah ok what's going on? But I think with the more I've had the more I've felt kind of in control...yeah because the second one I was extremely nervous probably to the point where I was shaking but with the third one I felt more in control and able to handle it a lot better (Interview 7)</i></p> <p><i>I did worry about the first one but last Thursday was the third one so no I was alright...I think you get a bit shocked when you have the first one...(Interview 1)</i></p> <p><i>but it's like anything you've got a picture of the theory of it but to actually go through it you don't realise and I guess at the end of it I seem to remember saying it wasn't a pleasant experience but it wasn't as bad as I thought...(Interview 2)</i></p> <p><i>Um yes...I mean having it done again I'm less concerned now that I know the procedure and what's likely to happen I'm less concerned about that...(Interview 8)</i></p> <p><i>Exactly. Knowing where you're going and lying up in the place whilst they organise all the materials and all the equipment and things round you and to know to say to them 'it's cold in this room give me an extra blanket round my feet'. (Interview 3)</i></p> <p><i>No I mean once I knew what to expect I think that helps to a certain extent...they do try and prepare you as much as they can it's easy to sort of say I didn't know this or I didn't know that but they do try</i></p>

		<p><i>their best to tell you everything if they can...but I knew what so expect the second time so yes that helped (Interview 5)</i></p> <p><i>um...but you're more prepared I mean you know what's going to happen and you know to say 'please can you give me a bit extra sedation' (Interview 9)</i></p> <p><i>Well I didn't know what was going to happen the first time anyway and the only thing I thought this time was it couldn't have been too bad because I've had it done before... (Interview 6)</i></p>
	- The CATH journey with complications	<p><i>I think my main worry was that my heart was going to start beating really fast again that was a definite worry because I remember how weird that felt and how uncomfortable that was...that really freaked me out and I was worried that was going to happen again but the only time I had that was when I first had it so I don't think that's likely to happen anymore but it's always like...oh what if that happens again...(Interview 7)</i></p> <p><i>and then the third one...I got really panicky when I was having it done and when I came to the fourth time I really didn't want to have it done I really got a sort of phobia I think...it seems the more I have it done the more I feel it... (Interview 10)</i></p> <p><i>Well I think I was more hesitant over the second one because he said something had gone wrong...he said it was stuck...so I was a bit...umm...concerned (Interview 1)</i></p> <p><i>I'd had a toe infection the week before and they were not sure if to go ahead with the procedure because of that...there was a bit of that, but of debate but finally they did it obviously because it was a separate area...but that was a bit anxious because I would have had to pack up and go home and have it done again but that was nothing to do with the procedure it was to do with my own personal circumstances at that particular time (Interview 8)</i></p>
	- Prior experiences	<p><i>No it didn't worry me at all <doctor's name> put me at ease the way he explained it to me it's just a needle that isn't going to finish me off I've had a heart bypass when I was in Bristol...didn't bother me at all...(Interview 4)</i></p>


		<p><i>...it was not hugely concerning because I've been through quite a lot and realised it's only a minor thing really and knowing how much it would help at the end of it really... (Interview 8)</i></p> <p><i>...And um when I had the first one I was really just used to hospitalisation by then and I was having so many tests done because of this operation (Interview 6)</i></p>
Trust in expertise		<p><i>First time it was mentioned to me at <place name> by the consultant who thought I would be better to have it done at <place name> 'cause they had more experience there and did them much more regularly...erm so in that respect I felt more confident going to <place name> (Interview 3)</i></p> <p><i>So it all comes down to trusting the doctors basically that they um know what they're talking about and they're not putting you through a procedure that's potentially dangerous in many ways...without there being good reason for it (Interview 2)</i></p> <p><i>I would say there's still that ok here we go you know but you're in the hands of experienced people and that makes a difference I think...(Interview 2)</i></p> <p><i>It'll be alright...and you know just having that faith and trust in people with the best will in the world, I know things go wrong but you have to put your trust in people because they are skilled and you have to trust them to look after you well. (Interview 5)</i></p> <p><i>As I say when you're not medically trained or scientifically minded you tend to take these things on face value...you know you just hope that the people you're seeing know what they're up to and I'm sure in this case they do... (Interview 9)</i></p>
Feeling connected	- Being involved	<p><i>you usually get one of the nurses come out, introduce themselves and say I'll be looking after you throughout the procedure I'll be at your head and if there's any problems you know...call out if you're feeling unwell or something's concerning you...and throughout the procedure they're constantly asking you 'are you alright <participant name>?' 'is everything ok?' (Interview 2)</i></p>

		<p><i>Yes I mean they just talked to me and explained to me...and I mean obviously they're going to explain what they're doing and anyway I was so dozy I wasn't concentrating you know I wasn't aware really of what they were doing but on the other hand they kept me informed the whole time (Interview 9)</i></p> <p><i>Not particularly (anything that's particularly helpful on the day) just keeping you informed is the main thing and talking to you...letting you know if there's a delay or something and they're all pretty good at that...(Interview 3)</i></p> <p><i>I think generally everyone's there to make sure you're ok and to make sure you know what's going on...I think apart from when your slot is I think they're always really good at updating you about what's going to happen...(Interview 7)</i></p> <p><i>It was enormously helpful (being talked to and kept in the loop) yeah reassuring I think...there were no signs that things weren't looking good but it's just that reassurance sort of keeps you calm and you just try and relax and let them do the procedure and deal with it you know...(Interview 5)</i></p> <p><i>I think it's explaining what would happen and saying 'well there might be a bit of a wait here' and sort of keeping me up to date with when I would be due down for the procedure...so yeah keeping me informed was helpful...(Interview 8)</i></p>
	- Kindness	<p><i>but I think they really do an excellent job because they, in a difficult situation, try to make you feel as much at ease as you can and they joke and they laugh as well to try and keep it light hearted...so as I say there's always someone keeping an eye on you...(Interview 2)</i></p> <p><i>Well they just chatted really about something and nothing...you know where've we come from and have we been on holiday...you know just sort of socialising a bit really...probably trying to take my mind off it...(Interview 1)</i></p>

	<p><i>And as I say the CATH lab people were...were extremely nice from that point of view...which makes all the difference to me the fact that they're looking at me as a whole person not just the bits that they're interesting in...(Interview 9)</i></p> <p><i>I liked him enormously he was extremely nice to me and absolutely charming and that makes you feel that actually this is all going to be ok and the rest of the staff you know his registrars and all the nurses attached to it and <name> who runs the appointments and things you know everybody is more than helpful... (Interview 9)</i></p> <p><i>throughout the staff have been amazing right through from the lady who does the booking the appointment the whole...I mean everyone's been so kind and just so supportive and um they've helped me in every way so I'm very grateful for that...(Interview 5)</i></p> <p><i>Yeah I think in...certainly the ones at <hospital name> the nurses were good in the day ward...the people who did catheterisation, the medical staff they were very you know good sense of humour, very light...upbeat I suppose is the word...that helped to relax you (Interview 8)</i></p> <p><i>Well the friendliness of the nurses (helps on the day) and the way they talk to you and just the general friendliness in the unit...they're pleasant, they talk to you, refer to you...tell you how long it was going to be...that type of friendly attitude within the department...They treated you as a human being to chat to rather than just here's another patient get them through the system...(Interview 3)</i></p> <p><i>I just tried to sort of put it out of my head and just try and relax and get on with it really...and the nurses were really nice one of the nurses held my hand the whole time and wouldn't let go of me...</i></p> <p><i>Um well when I actually got to the hospital and before it the staff there were so nice and sort of put my mind at rest but I'm still scared <laughs> but they were saying 'oh you'll be alright' you know and...so it was a good lot of people around me at the time... (Interview 10)</i></p>
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	<p>- Shared experience</p> <p><i>As I say if people ask me when they're waiting to go I say 'no it's fine honestly' because someone did that to me the first time and it got me through the first one... (Interview 10)</i></p> <p><i>I was aware in some respects of what the procedure might look like...and they show when someone goes in so poorly and has it done and they're walking around so much better so it's obviously nothing major...I suppose that gave me confidence as well... (Interview 3)</i></p> <p><i>...but if you're so nervous but the way the staff dealt with her they were so kind and tried to reassure her and I sort of went round and talked to her and said 'I've had it done a couple of times and I'm okay, it's alright they will look after you' (Interview 2)</i></p> <p><i>Well mostly friends that have had the same procedure and that's reassuring in itself because they've come through it... (Interview 5)</i></p>
	<p>- Faith and support</p> <p><i>Well she was just there for me really that was the main important thing that I wasn't there on my own...I think that was the main thing because it would have been difficult if I would have had to go home and cook my dinner things like that so with her being there that made it a lot easier (Interview 7)</i></p> <p><i>and you know I think I'd made my mind up before I went that you just sort of get on with it and we'll deal with each step at a time and I knew a lot of people were praying for me, I've got my faith as I said before and supportive husband so I think I just thought just relax about it you know they're looking after you just go for it and that's...I can't explain it any better really... (Interview 5)</i></p> <p><i>I suppose really just the feeling that although you're the one in the theatre having it done you're not on your own, it's that sense of people standing by you...you know God's on my side, my husband's on my side it's just knowing that you're sort of cared for (Interview 2)</i></p> <p><i>Yeah just I mean...just said she was going to come with me and I said 'it's alright honestly' but she did come...it was just as well afterwards having someone sort of the relief (Interview 10)</i></p>

Appendix G – SIP patient experience leaflet

What do staff think?	Your preferences	Royal United Hospitals Bath  <small>NHS Foundation Trust</small>
<p>As part of the research, we also asked staff how they help patients to cope with the cath:</p>	<p>Please use this space to write any questions you have or any preferences for the cath. For example some people want more information, some people might want their hand held or have someone chatting to them during the procedure.</p>	<div data-bbox="1431 549 1724 571">INSERT STAFF PHOTO HERE</div>
<p><i>'I think you are kind of the patients advocate...if they are frightened to allay their fears, you can relay to the consultant or the cardiac lab, you can make (the lab) fully aware of what they are frightened of, if they've got any requests it's your duty to make sure they are fulfilled, if they want someone to go in with them, or want someone to hold their hand...yeah I do feel that we are the ones that they can come to'</i> <i>(Respiratory Nurse Specialist)</i></p>	<p>Everyone is different. What would work best for you?</p> <div data-bbox="967 788 1285 1241"><hr/><hr/><hr/><hr/><hr/><hr/><hr/><hr/><hr/><hr/></div>	
<h3>Resources</h3>		
<ul style="list-style-type: none">• The Pulmonary Hypertension Association website: www.phassociation.uk.com• There will be waiting around on the day so patients suggest bringing a book or music to listen to (e.g. ipod).		
<hr/> <p><i>Thank you to all the staff and patients at the RUH who participated in this project.</i></p> <p><i>- Cate Anderson and Cara Roberts-Collins University of Bath</i></p> <hr/>		<p>Cardiac Catheterisation:</p> <p>What patients and staff have to say about it</p> <div data-bbox="1413 1321 1751 1337"><hr/></div>

Patients with Pulmonary Hypertension were interviewed as part of a research project about their experiences of the cardiac catheterisation procedure (cath). They talked about how they coped with it and what helped them through. Here are some of the things they said:



It's normal for patients to be nervous about having the cath but there are things we can do to manage this

'I knew more or less what to expect it's just that little bit of nervousness before you go in to have the procedure because although it's explained you still don't know how you're going to react when you actually go in to have the procedure done' (patient)

Insert picture of MTU or waiting area

What happens?

'they all tell you their names and what they are doing—'right it's ok we are going to cover you up now, preserve your modesty...and then it's the local anesthetic that's probably the worst bit because it hurts when it goes in but once that's in you can feel pushing at that point but you don't feel pain and you don't feel it inside it's quite strange...so I think they really do their best to make you feel as comfortable as they can in a bad situation...' (patient)

'... the first time is a bit more of a worry because you're not quite sure what you're going into behind those double doors....' (patient)

Insert picture of cath lab

What helps?

'Well the friendliness of the nurses (helps on the day) and the way they talk to you and just the general friendliness in the unit...they're pleasant, they talk to you, refer to you...tell you how long it was going to be...that type of friendly attitude within the department...They treated you as a human being to chat to rather than just here's another patient get them through the system...' (patient)

Insert cath team photo here

'...but if you're so nervous but the way the staff dealt with her they were so kind and tried to reassure her and I sort of went round and talked to her and said 'I've had it done a couple of times and I'm okay, it's alright they will look after you' (patient)

Appendix H – Patient passport

	Yes	No
Are you someone that would like to be distracted during the cath? E.g. Music, chatting, looking at something.		
Are you someone that wants to know all the details of the procedure?		
Would you like someone to hold your hand during the procedure?		
Are you someone that would prefer people not to chat to you too much and to leave you to approach the staff if you need them?		
Have you had any past experience of difficult medical procedures? E.g. medical complications or feeling panicky.		

Appendix I – SIP Lay summary

Why we did the study

Pulmonary Arterial Hypertension (PAH) is a chronic disease, which is monitored by a series of complex treatments including cardiac catheterisation (CATH). Research tells us that people can find the CATH procedure anxiety provoking, however, most people go through CATH without any formal psychological support. This study aimed to find out more about the emotional and psychological impact of having CATH and about how people manage this and get through repeat procedures. In doing this the study aimed to also provide recommendations to hospital staff for how they could best support people (practically and emotionally) through CATH.

What we did

Between October 2014 and January 2015 nineteen patients with PAH at the Royal United Hospital in Bath (RUH) were invited to take part in the research study. All nineteen had experience of at least two CATH procedures so could draw on their initial and subsequent experiences. Twelve of the nineteen patients replied to say they wanted to take part and ten of those were successfully contacted for an interview. Interviews were conducted in people's homes or over the phone and focussed on the experience of having CATH and on what had helped people to cope before, during and after the procedure. The ten patients who were interviewed were eight women and two men with an average age of 63 years (range 24-77 years old). They had experienced an average of three CATH procedures each (range 2-4).

What we found

The ten interviews were collated and read for common themes; there were four main themes which were identified (below).

1. A key theme was importance of recognising that going through CATH was an individual process and that there was no 'one way' to experience it. The fears people experienced were varied in nature and intensity and how they prepared themselves and coped varied also.
2. The importance of people's past experience was highlighted. The experiences people had prior to having CATH, as well as their experience of repeat CATHs, shaped how they viewed and coped with the procedure. It was as if patients were on a journey with the procedure, during wherein first CATH was totally unknown and each subsequent CATH influenced how they would feel in the future.
3. Thirdly patients unanimously spoke about the importance of being able to place their faith and trust in the expertise of medical professionals. Patients spoke of how this helped them to feel reassured and more confident in what was happening.

4. Finally, it was clear that something which helped people to cope throughout the whole experience of CATH was feeling that they were connected on a human level with staff, peers, family and their faith. Participants spoke of these connections giving them strength, reassurance and an ability to cope through a difficult procedure.

What recommendations did we make?

Out of these above findings a number of recommendations were made to the RUH, these included:

- The amount of information patients receive should be individually tailored so that those who want the bare minimum are given this and those who want to read more can access resources.
- A patient-centred leaflet and video should be developed so that people can read quotes from others who have been through the procedure and can see for themselves what would happen on the day of the procedure.
- The psychologist within the Pulmonary Hypertension (PH) team should be informed of anyone who has had negative experiences of hospital procedures in the past so that she can support and prepare them for the CATH.

The RUH in Bath have taken on board these recommendations and will continue to evaluate how people are experiencing the CATH procedure.

What did we conclude?

The results of this study provide an insight into how patients cope with the CATH procedure and how health professionals can promote this within the PH team at the RUH in Bath. The identified themes suggest that whilst perceptions of the CATH procedure are very individual, the importance of relationships with staff and trust in their expertise spanned different patients' experiences. Findings also suggest that improving someone's understanding of what will happen on the day of the procedure and increasing their sense of control can promote positive coping. The study findings have led to a number of service improvements and the RUH in Bath.

Appendix J – Author guidelines for Main Research Project

Aims and Scope

Early Intervention in Psychiatry publishes original research articles and reviews dealing with the early recognition, diagnosis and treatment across the full range of mental and substance use disorders, as well as the underlying epidemiological, biological, psychological and social mechanisms that influence the onset and early course of these disorders. The journal provides comprehensive coverage of early intervention for the full range of psychiatric disorders and mental health problems, including schizophrenia and other psychoses, mood and anxiety disorders, substance use disorders, eating disorders and personality disorders. Papers in any of the following fields are considered: diagnostic issues, psychopathology, clinical epidemiology, biological mechanisms, treatments and other forms of intervention, clinical trials, health services and economic research and mental health policy. Special features are also published, including hypotheses, controversies and snapshots of innovative service models.

Outline of page requirements

Articles reporting original work that embodies scientific excellence in psychiatry and advances in clinical research (maximum word count for text 3000; abstract 250);

Appendix K – MRP Ethical approval letter



Health Research Authority

National Research Ethics Service

NRES Committee North West - Preston

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7818
Fax: 0161 625 7299

30 June 2015

Miss Cate Anderson
Department of Psychology
University of Bath
Claverton Down, Bath
BA2 7AY

Dear Miss Anderson

Study title: An experimental study to investigate the impact of a psycho-educational video delivered either by a peer or a professional on self-stigmatising attitudes in first episode psychosis.

REC reference: 15/NW/0517

IRAS project ID: 171905

The Research Ethics Committee reviewed the above application at the meeting held on 26 June 2015. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Mrs Carol Ebenezer, nrescommittee.northwest-preston@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

Summary of discussion at the meeting

The Chair contacted you by telephone and thanked you for being available to discuss the study. The Committee told you that this was a very interesting and well put together application.

Social or scientific value; scientific design and conduct of the study

The Committee asked for clarification of how the videos would be scripted.

You explained that it would look as though the people on screen were having a conversation but where the peer was giving the answers it would come from their personal experience. The peer video would probably use different language and terminology to the professional video, so the questions would be scripted but not the answers. In a similar video undertaken this week, the peer had some notes to ensure they included everything they wanted to talk about. You confirmed for the Committee that time 1 and time 2 were immediately before and after the intervention.

The Committee asked whether the feedback on the videos would be audio recorded or whether only notes would be taken.

You stated that only notes would be taken but that you have still provided for consent to the use of direct quotes if appropriate.

The Committee asked how participants would be randomised.

You stated that they would be stratified and you would take into account various factors when splitting into groups, e.g. age, gender and for how long they had the diagnosis. You have discussed the method with a statistician.

The Committee asked how you would know this was first episode psychosis.

You said that you would include anyone in the Intervention Service. You also told the Committee that participants could take as long as they needed to complete the self-report measure.

Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)

The Committee asked whether travel expenses would be paid or whether the intervention would tie in with other trips.

You confirmed that you would tie in with other trips to the local service so expenses would not be necessary.

The Committee pointed out that the demographic asks for a date of birth which is an identifier and asked whether the age could be requested instead.

You agreed to this.

You had no questions for the Committee.

The Committee noted that participants in this study would be getting something additional to what they would get if not in the study.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Covering letter on headed paper v1.0 300415]	1.0	30 April 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor insurance or indemnity v1.0 300415]	1.0	30 April 2015
Letter from sponsor [Sponsorship_letter_approval v1.0 300415]	1.0	30 April 2015
Other [Summary CV for supervisor 2 version 1.0 300415]	1.0	30 April 2015
Other [Socio-demographic information v1.0 300415]	1.0	30 April 2015
Other [Programme for the psycho-educational video v1.0 300415]	1.0	30 April 2015
Participant consent form [Consent Form v1.0 300415]	1.0	30 April 2015
Participant information sheet (PIS) [Participant_Information_Sheet_v1.0 300415]	1.0	30 April 2015
REC Application Form [REC_Form_05062015]		05 June 2015
Research protocol or project proposal [Research protocol version 1.0 300415]	1.0	30 April 2015
Summary CV for Chief Investigator (CI) [Summary CV for Chief Investigator version 1.0 300415]	1.0	30 April 2015
Summary CV for supervisor (student research) [Summary CV for Chief Investigator version 1.0 300415]	1.0	30 April 2015
Validated questionnaire [The self-stigma of mental illness scale - short form]	1.0	30 April 2015
Validated questionnaire [Rosenberg self-esteem scale]	1.0	30 April 2015
Validated questionnaire [The Empowerment Scale]	1.0	30 April 2015
Validated questionnaire [New general self-efficacy scale]	1.0	30 April 2015
Validated questionnaire [The 'Goals and Success' subscale of the Recovery Assessment Scale – revised]	1.0	30 April 2015

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol

- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/NW/0517

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Patricia Wilkinson
Chair

E-mail: nrescommittee.northwest-preston@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

*Copy to: Professor Jane Millar
Ms Hannah Antoniadou, Research and Development*

NRES Committee North West - Preston

Attendance at Committee meeting on 26 June 2015

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mr David Abbotts	Lay member	Yes	
Professor Anoop Chauhan	Consultant Cardiologist	Yes	
Mr John Dalton	Lay Member	No	
Mrs Debbie Foord	Community Psychiatric Nurse	No	
Professor Carol Haigh	Professor of Nursing	No	
Ms Eleanor Jolley	Lay Member	Yes	
Mrs Kate Kilshaw	Radiographer	Yes	
Dr Rob Monks	Senior Lecturer Department of Nursing	No	
Professor Videsh Raut	Consultant Orthopaedic Surgeon	Yes	
Mrs Valerie Skinner	Nurse (Retired)	Yes	
Mrs Vasanthi Vasudevan	Diabetes Research Nurse	No	
Dr Patricia Wilkinson	General Practitioner/ Chair	Yes	
Dr Hawys Williams	Lay Member	No	
Dr Karen Wright	Senior Lecturer Mental Health	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Regina Caden	REC Assistant
Mrs Carol Ebenezer	REC Manager

Appendix L – MRP interview script without identifiable details

Questions for the video

I will introduce you and say that we're going to have a chat about psychosis and recovery.

CA asks - How would you describe what psychosis is, to someone who has never heard the word before?

Presenter talks around below points

- Individual – can look very different for different people.
- Common symptoms (e.g. strong beliefs, hallucinations) – bring in any examples you want.
- Describing the wider context of experiencing psychosis – could bring in any examples you like of other stresses happening or how psychosis might impact on sleep, relationships etc.

CA asks - What is your understanding of what causes psychosis?

- It's no one's fault, anyone could develop psychosis under certain conditions.
- Psychosis is very complex and causes can be different for different people.
- Can bring in any examples you like

CA asks - Where can people go to seek help for Psychosis?

- Talking about referral to Early intervention service – how to seek help.
- Can bring in examples of how you sought help/how someone in your service might seek help.

CA asks - How can the early intervention service help?

- Examples of different work the early intervention team do (e.g. care-coordinator, individual work, groups, personal goals).
- Can talk through work you did with the team/work you do with service users.

CA asks - The early intervention service focus on recovery in psychosis – can you tell me a bit about what recovery means for you?

- You can talk about anything that's been important to you/a service user in your/their recovery – what helped, what were the signs of recovery, hopes and plans for the future.

CA asks - Do you have any take home messages for other people experiencing psychosis?

- Anything you want to say that you think is important for people to know about psychosis and recovery.

Appendix M – MRP Qualitative feedback collected after the video

1. What did you find most useful about the video you just watched?

2. What did you find least useful?

3. How competent did the presenter seem?

Completely incompetent _____ Completely competent

4. How reliable did the presenter seem?

Completely unreliable _____ Completely reliable

5. How trustworthy did the presenter seem?

Completely untrustworth _____ Completely trustworthy

6. How persuasive was the presenter?

Not at all persuasive _____ Very persuasive

7. How much did you relate to what the presenter was saying?

Not at all _____ Very much

8. How inspiring was the presenter?

Not at all inspiring _____ Very inspiring

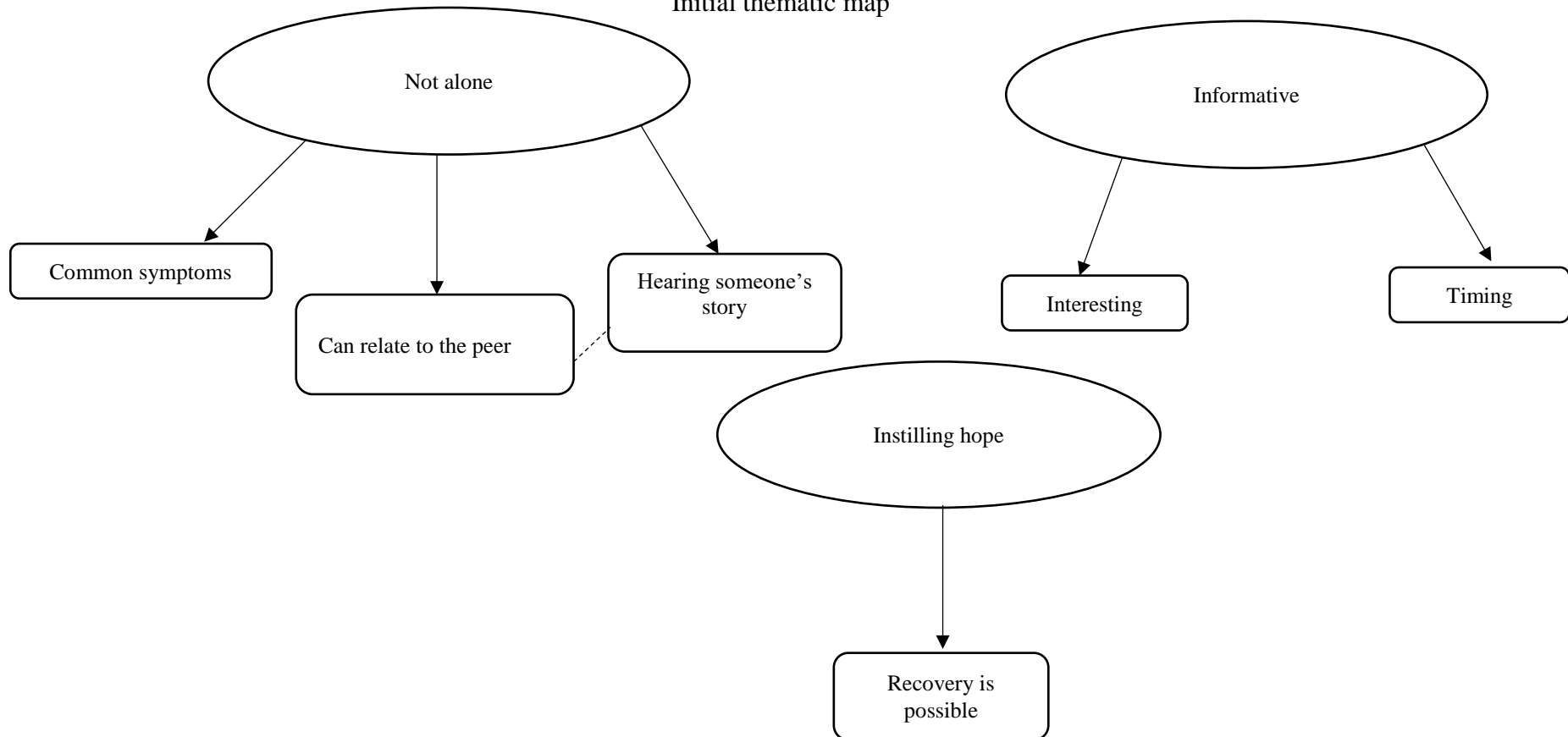
9. Do you have any other feedback on the video you just saw?

Appendix N – MRP Proposed statistical analysis

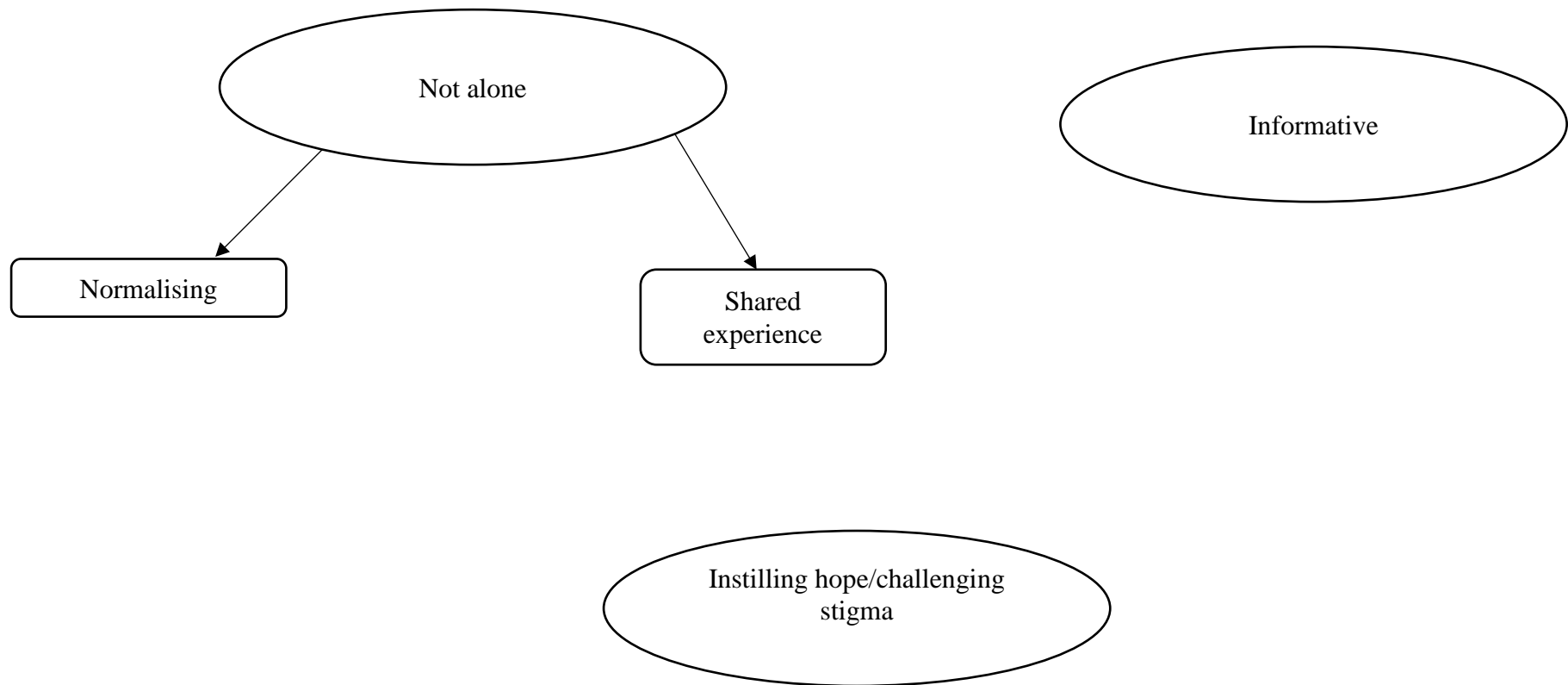
The original analysis plan was as follows. Socio-demographic data and descriptive statistics would be presented in tables. A series of independent t-tests would be used to test for differences between the two groups in terms of baseline variables. To investigate the first and second hypotheses, 2x2 repeated measures ANOVAs (time x group) would be used to assess main effects of the intervention and interactions. Any interactions found would be followed up with t-tests. To analyse the final hypothesis, the components of the model would be correlated against one another and a multiple regression would explore the relationship between self-stigma, social mediators and goal directed behaviour.

Appendix O – MRP Thematic maps

Initial thematic map



Final thematic map



Appendix P – MRP Table of themes

Informative		<p>Informative for people who don't know what it's about. Participant 20</p> <p><i>'It was good to have more information about where you can go to get help.'</i> Participant 15, professional condition</p> <p><i>'Found it interesting what was being talked about in the video.'</i> Participant 7, professional condition</p>
Feeling less alone	Normalising experiences	<p><i>'Realising that the symptoms were common because they have felt quite alien at times.'</i> Participant 11, professional condition.</p> <p><i>'Literally described everything I've been through like the example.'</i> Participant 6, professional condition.</p> <p><i>'Interesting to see how people have similar experiences.'</i> Participant 10, professional condition.</p> <p><i>'I liked the part about causes...that anyone under pressures can develop it under the right stresses and traumas.'</i> Participant 12, professional condition</p>
	Shared experience	<p><i>'I can relate to what she was saying about how she feels even better than before. I feel more equipped for life having experienced psychosis.'</i> Participant 2, peer condition.</p> <p><i>'I found the video quite interesting and could relate to what she's saying. I was surprised about how much I could relate with how strongly she believed things.'</i> Participant 14, peer condition.</p> <p><i>'Definitely found similarities of dealing with mental health issues like with the swimming and going to the gym...'</i> Participant 18, peer condition.</p> <p><i>'Hearing someone else's experience and their story.'</i> Participant 1, peer condition.</p> <p><i>'The fact that it was someone who had experienced psychosis...more</i></p>

		<p><i>believable coming from someone who's been through it rather than studied it conceptually.</i> Participant 8, peer condition</p> <p><i>'She went through it as well.'</i> Participant 16, peer condition.</p> <p><i>'Nice to hear the same sort of experiences...you feel less alone.'</i> Participant 13, peer condition.</p>
Challenging stigma and instilling hope		<p><i>'Dunno I guess it's kind of good for people...shows recovery is possible and that it's possible to get off all medication..'</i> Participant 9, peer condition</p> <p><i>'Good to see someone who's been through something and is doing well. It gives me hope for the future...'</i> Participant 2, peer condition</p> <p><i>'Nice to see someone succinctly define psychosis in a way that is comfortable and not stigmatising.'</i> Participant 13, peer condition</p> <p><i>'The presenter came across as 'normal' ...no visible symptoms of psychosis.'</i> Participant 8, peer condition</p>